

In Vitro Fertilisation and Multiple Births:  
International Context and Policy Consideration

Submitted by Victoria Jane Coven to the University  
of Exeter as a thesis for the degree of  
Doctor of Philosophy in Sociology in  
December 2013

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## **ABSTRACT**

### **IN VITRO FERTILISATION AND MULTIPLE BIRTHS: INTERNATIONAL CONTEXT AND POLICY CONSIDERATION**

In Vitro Fertilisation (IVF) may be viewed as a sociological problem because its widespread adoption has influenced the structure of the family unit. This in turn has had consequences for wider society and especially for health and social care institutions. A key objective of this study is to provide further theoretical development of the sociology of IVF initiated by Karen Throsby. Throsby takes a feminist approach and critically analyses discourses from women and couples engaged in the IVF process. Much of her work focuses upon IVF failure. Throsby situates IVF within 2 cultural narratives; 1) Reproduction is normal and natural, and 2) IVF is successful. She finds that the patient's experience of the IVF process produces a profoundly gendered discourse orientated towards locating the self and engagement with the treatment as 'normal'.

My investigation situates IVF within the same cultural narratives, and how they contribute to the phenomenon of multiple births that result from the adoption of this method of assisted conception. I investigate how public health policy may reduce these types of pregnancy for potential parents undergoing fertility treatment in the UK. Specifically, my research looks at the types of support that clinics in the UK are offering patients to decrease stress and distress, and whether and how such support mechanisms incorporate government mandates to decrease the multiple birth rate at UK clinics. My research question is therefore broad sociologically as I have dissected narratives contributing to the problem of multiple births and within the context of these narratives have sought to investigate how patient support in the form of counselling could be implemented as a policy response and encourage resistance or disruption of these narratives. An objective of this research was to discover if counselling could act as a forum to discuss and inform a patient about

the benefits of a single pregnancy; the implications of multiple embryo transfer and explore any patient negative response to SET. Secondly, there is some evidence that counselling may be effective in decreasing stress and distress surrounding the procedure for some patients and so may also help to maximise the chances of successful implantation of the single embryo. Throsby's research focused upon the naturalisation of IVF 'success' and resulting impact this had on the location of the patient's self-identity within the context of her medical condition. This study acknowledges the naturalisation of multiple embryo transfer techniques. Throsby's observation was that the naturalisation of both treatment success and multiple embryo transfer can be harmful for the emotional and physical health of the individuals engaged in the IVF process. However she suggested that resistance to the IVF process was possible and observed it arising spontaneously through the process of some patients' engagement with it (Throsby 1994:43). However through a Foucauldian perspective it is possible to speculate that because the patient's perception of their self-identity as an infertile woman within the context of treatment is fluid, such resistance is difficult. Patient resistance can help to redefine the cultural narratives inherent in the procedure. I extend Throsby's work by proposing that counselling offers a site for reflection within the clinical treatment cycle. Through engagement in counselling a patient may be able to more fully understand and contemplate their position in relation to each of the clinical processes. With professional counselling assistance a patient may find that such reflection can allow for an exploration of and relocation of their self-identity within the cultural narratives that surround IVF.

Multiple births occur because women receiving IVF treatment regularly have more than one embryo transferred into their uterus during a treatment cycle. The medical literature suggests that multiple births are detrimental to the health and well being of women using IVF and the children they bear. Multiple births also place stress on public health care. Accordingly, some countries have introduced legislation or regulations to limit the number of embryos transferred in an effort to decrease multiple birth rates. In the UK, policy is currently being implemented to encourage single embryo transfer (SET) for suitable patients. My study provides an analysis of

how this policy is being incorporated with existing policy surrounding the IVF procedure, specifically in the implementation of counselling. My findings indicate that SET is often met with resistance from users of IVF. My analysis suggests that, while existing cultural narratives leave little room for women to resist IVF practices such as those leading to the acceptability of multiple births, counselling could provide a space for such resistance. I use a Foucauldian framework in this analysis.

My research methods included qualitative interviews with fertility counsellors. This gave me valuable perspectives about the current administration of counselling in fertility clinics. Another key objective of this study is to “give voice” to the users of IVF. Therefore, to gain insight into the patient’s opinions about and experiences surrounding the IVF procedure I undertook an in-depth analysis of online patient Internet support sites. In addition I used observational data, and reflection upon personal experience to gain insights into patient’s experiences of the IVF procedure. To support this investigation, statistics, data and information from the UK, Europe and other countries have also been examined. This investigation concentrates on support services in the United Kingdom and ends with some recommendations for the promotion of and reference for these valuable services in conjunction with promoting policy to reduce multiple births. This work, in the form of both a sociological and policy analysis aims to contribute towards ongoing developments and debates regarding equitable administration of IVF fertility treatment in the UK.

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## **LIST OF ACRONYMS**

ART Artificial Reproductive Technology

ASRM American Society for Reproductive Medicine

BCA British Counselling Association

BICA British Infertility Counselling Association

CDC Center for Disease Control (US)

CQC Care Quality Commission (UK)

DI Donor Sperm Insemination

eSET Elective Single Embryo Transfer

ESHRE European Society of Reproduction and Embryology

FSHs Follicle Stimulation Hormones

GIFT Gamete Intra Fallopian Transfer

GnRH Gonadotropin Releasing Hormones

HFEA Human Fertilisation and Embryology Authority (UK)

HGG Human Chorionic Gonadotropin

ICSI Intracytoplasmic Sperm Injection

IUI Intrauterine Insemination

IVF In Vitro Fertilisation

NHS National Health Service (UK)

OHSS Ovarian Hyper-Stimulation Syndrome

PCTs Primary Care Trusts (UK)

RGT Reproductive Genetic Technology

ROCG Royal College of Obstetricians and Gynaecologists

SART Society for Assisted Reproductive Technologies

SET Single Embryo Transfer

SOGC Society of Obstetricians and Gynaecologists of Canada

## INTRODUCTION

This thesis explores the phenomenon of multiple births arising from the widespread use of IVF. Aggressive techniques are employed which introduce multiple embryos into the uterus of patients without due consideration of the consequences of multiple births for patients, their children or society. Multiple births following IVF have been identified as a problem for health systems and wider society. The Human Fertilisation and Embryology Authority has introduced regulations to reduce their incidence through the mechanisms proffered in the Human Fertilisation and Embryology Act 2008. All UK infertility clinics are required to promote SET and aim to limit their IVF multiple birth rate. My research explores the effect of legislation that restricts IVF practice in an attempt to reduce multiple births.

My research question is broad sociologically as I have dissected narratives contributing to the problem of multiple births and within the context of these narratives sought to investigate how patient support in the form of counselling could be implemented as a policy response. An objective of this research is to discover how patient support, particularly in the form of counselling, can be an important tool to promote SET. Clinicians have a duty to 'do no harm' as a core element of the Hippocratic Oath. Eliminating the health problems that occur as a consequence of multiple embryo transfer techniques is a vital professional responsibility. Any patient's successful engagement with SET as a primary treatment option is dependent upon their complex emotional response to SET as a treatment choice. My proposition is that SET should be promoted and implemented within IVF clinics in the UK and that counselling could be more comprehensively integrated into the culture of UK infertility clinics and used as a vessel to advocate SET. Decisions about infertility as a disease require input from those who are suffering from this disease and the counselling facility within the IVF clinic could be a forum to encourage such input.

My aim is to investigate the role of counselling as a policy response to multiple births as in the UK the government has an apparatus to regulate IVF treatment.

Additionally, I aim to contribute to the sociological understanding of IVF, focusing specifically on practices of multiple embryo transfer, policy responses, and counselling. As part of a collaborative reproductive healthcare approach, the infertility counsellor could have a critical role in educating both patient and clinic staff about the multifaceted issues surrounding SET. In this way the counsellor can act as an interface between the clinician and the patient by better interpreting and exploring their emotional needs while clarifying the practical and medical health aspects of the SET process. Currently every patient under law must be given the offer of counselling when embarking upon IVF treatment. There are vast variations in provision of counselling in IVF clinics in the UK. If the provision of counselling were to be expanded in UK clinics and endorsed by HFEA policy then counselling may act as a forum to discuss and inform a patient of the benefits of a single pregnancy; the implications of multiple embryo transfer and explore patient resistance to SET. HFEA policy currently is in place to decrease multiple births in IVF clinics and this may be expanded incorporate counselling as a vehicle to promote SET. Also, if counselling is effective in decreasing stress and distress surrounding the procedure for any patient, it may also help to maximise the chances of successful implantation of the single embryo and therefore negate the perceived necessity of implanting multiple embryos. It is my belief that an increased role for counselling to implement SET would be likely to enhance its appeal and usage and promote articulation of the voices of patients.

Foucault's work on power structures and medical technology postulates that medicalisation allows power based on technical capacity rather than moral consideration. This power then becomes normalised or naturalised, encroaching on the everyday lives of the individual and eroding their status (Foucault 1980: 146-65). I argue that counselling may provide a site of resistance to the overwhelming medicalisation of infertility treatment and a way of vocalising the desires, hopes and myriad of other feelings that are invoked through gaining access to IVF. Through Foucauldian lenses I argue that the discourse that is promoted within the office of the counsellor is a unique space to allow IVF patients to explore their feelings both to single embryo transfer and to the IVF procedure

itself. If proffered professionally the counselling offer can serve as a type of sanctuary to air feelings and talk about the vast array of different and difficult medical procedures that any one patient may experience. Discussion may help to clarify the procedures themselves and analyse any patient's feelings about the clinical processes. The counselling room can provide a patient with a refuge away from the largely value loaded procedures and systems that constitute the infertility clinic itself and through which any individual patient may be processed for many months and often years.

My research question arose from a concern about the effect of IVF has upon the multiple gestation rate and the consequences of this effect for the IVF child, the pregnant mother, the IVF parents, the health care facilities that care for such babies and wider society as a whole. My attention was drawn to this issue whilst a patient of IVF in Canada in 2001. At that time I was an MA student at the University of Guelph studying public health policy and its effectiveness in curbing underage smoking. My interest in public health policy developed from my undergraduate degree taken at the University of Exeter in Law and Society. This degree combined law and sociology modules. Consequently I became interested in the development of legislation and social policy and the social processes involved.

During my time in Canada I spent several years as a patient of IVF clinics. As a result of my experiences as a patient at the clinics some this study developed as a piece of "insider" research. Over an extended period of time I was able to attend support groups, waited for many hours for ultrasounds and conversed with other patients and talked to a variety of clinicians and clinic staff. I shared in my fellow patient's joys and sorrows and felt that my experiences as a recipient of services clarified some of the difficulties that we struggled with and their wider implications for IVF as a public health provision. My role as a user of the IVF services in Canada was instrumental in helping to shape and inform this study.

I was fortunate to give birth to four healthy children, two of which are multiples. My twins are identical. This was a result of the division of a single embryo, rather than

the implantation of more than one embryo. Whilst in the IVF clinic in Toronto, undergoing my first IVF embryo transfer, the clinician who was transferring the embryo via a needle into my uterus verbally explained that on this occasion he was going to transfer three embryos and that if more than two of them implanted he would recommend a reduction. This conversation took place during a surgical procedure that I was medicated for. It raised alarms for personal and ethical reasons. The experience led me to investigate the phenomenon of multiple pregnancies that result from IVF and later instigated the desire to write this PhD thesis.

My aim was to investigate viable public policy measures that would alleviate the suffering and cost to women, children and to wider society as a result of these IVF practices. As a sociologist, I made a decision to situate my social policy plea within a critical Foucauldian perspective. I felt that this body of theory accurately harmonised with many aspects of the IVF process. My discussion of this can be found in chapter 5. The IVF industry and related pharmaceutical industries have been fundamental in shaping women's corresponding readiness to engage in the technology. In some countries social policy has responded to this. In the UK, public policy has developed in response to the widespread adoption of IVF since its first success in 1978.

My work begins in chapter 1 with a descriptive account of the IVF process itself and explains how the IVF process has influenced multiple birth rates. I then give in chapter 2 a more detailed overview of IVF and outline literature pertaining to IVF regulation in the UK where IVF is regulated by the Human Fertilisation and Embryology Authority (HFEA). Because I was living in North America at the time that this social problem of multiple births became visible to me, I felt that it was important to situate the IVF procedure in an international context. Chapter 3 takes an in-depth look at this. This chapter reviews public policy documentation regarding IVF and multiple births in Europe. I also reflect upon personal investigations that I made into the treatment services where I was an IVF patient in Canada. My personal experience of clinics in Canada and my discussions with clinicians, nurses and other IVF patients lead me to believe that the frequently



insufficient patient support was invaluable to the IVF process and could be incorporated into any clinic's mandate to reduce multiple births and promote SET. Chapter 4 is an analysis of IVF and psychological support, counselling pertaining to IVF, counselling in UK clinics and public policy governing counselling and IVF. In chapter 5, the literature review, I situate my investigation within a sociological paradigm. Chapter 6 outlines my research methods.

The next part of my thesis is where my original research takes place. Chapter 7 presents findings from UK infertility clinic patient information and illustrates the variable nature of patient support across the 86 clinics that offer IVF in the UK. The chapter then goes on to detail my interviews with IVF counsellors in the UK concerning their counselling roles in clinics across the UK. I wished to understand the current or potential role of counselling with regard to patient support and information about multiple births and single embryo transfer. I presented the findings of my research at a conference to the British Infertility Counselling Association (BICA). Chapter 8 details my search to gain insights into IVF patients' feelings and experiences surrounding multiple births and single embryo transfer. I do this by analysing chat room evidence from Internet infertility support group sites. The patients involved in this part of the study were all UK residents. I accessed patient perspective via chat room representations rather than face-to-face interviews because of access and sampling difficulties. I conclude my investigation with recommendations for public policy pertaining to the reduction of multiple births for IVF clinics in the UK and a discussion of my findings in the context of existing sociological studies of IVF.

## **CHAPTER ONE**

### **MULTIPLE BIRTHS AND IVF: A SYNOPSIS**

#### **1.1 Overview of Multiple Births in the UK**

Multiple births are a problematic side effect of IVF. The multiple birth rate has increased because women receiving IVF treatment usually have more than one embryo transferred into their uterus during a treatment cycle. Non-iatrogenic occurring multiple births are a rarity and occur in less than 1% of all deliveries (Chitayat and Hall 2006). In Caucasian populations, twins occur in about one in 250 pregnancies, triplets in about one in 10,000 pregnancies, and quadruplets in about one in 700,000 pregnancies (ASRM 2012). The multiple birth rate has been drastically distorted by uptake of IVF. Figures from 2011, published in 2013, show that multiple births account for 16.1 percent of the total live births in England and Wales each year (Office of National Statistics 2013). In response to this the National Institute for Health and Clinical Excellence (NICE) issued new health guidelines in September 2011 regarding antenatal care to be provided to women carrying such pregnancies. According to NICE, women should receive no fewer than six scans, and be offered emotional support and information on topics including preterm labour and breastfeeding, by a range of healthcare professionals who are used to dealing with multiple pregnancies. The guidelines were a response to disparities in care in England and Wales for higher risk multiple pregnancies (NICE 2011).

##### **1.1.1 Multiple Births and Health Risks**

Multiple births are detrimental to the health and well-being of families using IVF and place a stress on the administration of public health care. The Royal College of Obstetricians and Gynaecologists have recently discovered that there is an additional 23% increase in the chances of premature birth in IVF twins compared

with natural twins (RCOG 2012). The risk of death before birth or within the first week of life is more than four times greater for twins and seven times greater for triplets than a single baby. There are higher risks of fetal abnormality including growth restriction, neurological defects and cerebral palsy (5 times more likely for twins, 18 times more likely for triplets) for children who are products of multiple births. Multiple births are a tremendous strain on a woman's body and there is also a higher risk of miscarriage, anaemia, hypertension and labour complications (Luke *et al.* 1996:108). This myriad of health risks places an enormous financial burden on the family and society (Mangham *et al.* 2009:322). Additionally these babies are most often born prematurely and have a low birth weight requiring a long time in an incubator. Between 40-60% of IVF twins are transferred to neonatal care units when they are born, compared to 20% of IVF singletons (Cloherty 2008:93).

#### 1.1.2 Multiple Births and Public Health Care Costs

In a study of preterm public health care costs, Mangham *et al.* did a cost analysis and found that treating premature babies, a growing number of whom are multiples, cost England and Wales £2.946 billion in 2006 (Mangham *et al.* 2009:322). These costs were mostly linked to neonatal care such as incubation and hospital readmissions. Costs during the neonatal period are responsible for 92% of the incremental cost per preterm survivor (Mangham *et al.* 2009:323). This study used live birth and pre-term birth data from England and Wales in 2006. The total cost of preterm births to the public sector was estimated to be £2.946 billion over childhood and an inverse relationship was identified between gestational age at birth and the average public sector cost per surviving child. The incremental cost per preterm child surviving to 18 years compared with a term survivor was estimated at £22, 885. The corresponding estimates for a very (under four pounds in birth weight) and extremely preterm (under two pounds in birth weight) child were substantially higher at £61,781 and £94,740 respectively. These costs were broadly in line with another modelling study of the costs of preterm birth, which has estimated the incremental lifetime costs of a preterm birth in the United States at \$51,600. However in the United States these costs are largely borne by the

individual and not the public sector (Institute of Medicine 2007).

### 1.1.3 Multiple Births and Psychosocial Risks

In addition to health risks, multiple births can add potential psychosocial risks to the family unit. One study revealed that in a triplet pregnancy for the first 6 months of the infants' lives parents and caregivers provided an average of 197.5 hours care per week (Launslager, 1993:123). Reported problems for parents include unrealistic expectations about parenting, marital strain, separation, divorce and maternal depression (Garell *et al.* 1995:2748). One study reported that up to 10% of parents of twins consider or actually separate during the first year after birth, compared to 6% of singleton infants (Sen *et al.* 2005). In 2008, a study from Helsinki University Central Hospital in Finland studied artificial reproductive technology (ART) parents of 91 sets of twins and 367 singleton babies, alongside a control group of parents who conceived naturally, resulting in 20 sets of twins and 379 singleton babies. The mothers and fathers in each group were separately assessed in relation to depression, anxiety, sleeping disorders and social dysfunction at three stages: while in the second trimester of pregnancy, when the children were two months old, and when they were one year old. The researchers found that during pregnancy, mothers in the control group had more depressive symptoms and greater anxiety than the mothers utilising artificial reproductive technology for both twin and singleton pregnancies. At the same stage, fathers in all groups had similar but lower than the mother's levels of anxiety. At the two months stage, and at one year after the birth, it was found that mothers of twins in both the ART group and the control group had more depressive symptoms and greater levels of anxiety. ART fathers of twins had more depressive symptoms at the two-month point than fathers of singletons; these figures were comparable to the men in the control group. However, fathers of twins in the ART group reported higher levels of social dysfunction. At one year, fathers of twins in both groups tended more towards depression and anxiety, as well as reporting more sleeping difficulties than fathers of singletons (Vilksa *et al.* 2009). The researchers indicated that more support should be given to all parents, especially fathers, in ART, as it

may be the case that fathers find the transition to parenthood more difficult and have generally less social support in place than mothers, even though the results showed that twin parenthood, not ART, is what seems to have a negative impact on mental health. Nevertheless, speaking at the 2008 annual meeting of the European Society of Human Reproduction and Embryology, Dr Unkila-Kallio said, 'We believe it is important to reduce multiple pregnancies worldwide by introducing single embryo transfers', adding that 'our results on parental mental health of twin parents provide further evidence to support this policy' (ESHRE 2008).

A study supported by the Twins and Multiple Birth Association (TAMBA) in the UK found that nine months after a multiple birth, 28 per cent of multiple birth families had split up compared to 24 per cent of other families. Financial pressures were a common reason given for family breakdown, according to the research by Birmingham University's School of Social Policy. Sixty two per cent of multiple birth families said they were financially worse off after their babies were born, compared with forty per cent of families with 'singletons'. It was twenty per cent less likely that a mother would return to work 9 months after a multiple delivery (TAMBA 2010).

A follow-up study of mothers and triplets describes the need for psychiatric intervention for the mother, father, or both parents, as well as the frequent use of psychotropic medications, particularly among mothers of triplets (Robin *et al.* 1992:143). Another study concluded that mothers of multiples are at increased risk of poorer emotional well being (Sheard *et al.* 2007). This indicates a need for both IVF clinicians and patients to focus on the psychological benefits of a singleton birth. A study reported in the journal *Paediatrics* concluded that mothers of multiple births had 43% greater odds of having moderate/severe, 9-month postpartum, depressive symptoms, compared with mothers of singletons. The authors recommend greater attention in paediatric settings to address maternal depression in families with multiple births (Choi *et al.*, 2009:1148).

From my personal experience of the IVF process and my interactions with other patients, I found that couples seeking IVF treatment have very often suffered stress

from unsuccessful conception over several years. When approaching a clinic for treatment they may not be fully informed of the IVF procedure and may not realise or be advised of the risks associated with multiple births or the long-term effects on their family or society. In addition to emotional pressures many patients receiving IVF are under extreme financial strain because of the high costs involved. They may wish to pursue the most aggressive treatment possible because they are unable to come back and repeat the process if it is unsuccessful. When eventually falling pregnant with multiples, these parents may have waited a very long-time and undergone many hardships both emotionally and financially. For years their focus may have been upon getting pregnant. This means that they may differ from non-IVF parents of multiples because they may have given very little consideration to the reality that their babies may need support for health issues or that they may need practical and emotional support as a family unit. These parents are extra vulnerable, as they will have to adapt from an infertile life to a life with multiples and the variety of health issues stress, anxiety, and depression, financial and other issues that such a lifestyle change may bring.

## **1.2 Multiple Births as a Public Policy Issue**

It is my opinion that effective social policy creates conditions to protect the institution of the family, whatever its structural form and subsequently offers stability to wider society. However it is apparent that public policy does restrict the ideals of choice and liberty in procreation for individuals who use IVF. Drawing on observations and literature it is an assumption of this thesis that, without restrictive policy it appears the practice of IVF has become heavily influenced by market mechanisms driven by the interests of doctors and pharmaceutical companies and fuelled by the desires of patients. In the UK there are not many restrictions governing reproductive technologies but there are public policy frameworks in place to govern certain aspects of the public provision of such technologies. These policies are currently administered under the umbrella of the Human Fertilisation and Embryology Authority (HFEA).

### 1.2.1 Current UK Public Policy: Human Fertilisation and Embryology Authority (HFEA).

The United Kingdom is an international forerunner in the establishment of legislation governing the IVF procedure. The Human Fertilisation and Embryology Act 1990 (amended by The Human Fertilisation and Embryology Act 2008) has been the umbrella for much regulation governing many aspects of the technology including restricting the number of embryos transferred during any IVF cycle to 3 in an attempt to limit multiple births. The HFEA was established in 1991. Its statutory and regulatory responsibilities include the licensing of infertility and research centres, regular inspections of licensed premises, the investigation of adverse incidents, the registration of data about IVF cycles and the provision of information. In February 2002, the HFEA reviewed its embryo transfer policy because it felt it to be inadequate. New policy recommendations came into place, which allowed clinics to limit the number of embryos transferred during any one IVF cycle from 3 to 2 in women under 40 years of age. This was done because of the continuing levels of multiple births associated with IVF. In 2007 the HFEA created new policy to minimise the rates of multiple births further again. Key elements of the policy were:

1) to bring the UK IVF multiple birth rate to 10% over a staged period

2) to set interim targets towards this 10% goal. These targets apply an upper limit multiple rate to all clinics. The first target was 24% (the national average at that time) and was applied in January 2009. In January 2010, 20% was set as a multiple birth target. The latest policy was introduced in January 2011. It proposed a maximum multiple birth rate of 15% across clinics. This came into effect in April 2011 and applies to all IVF births from treatments started between April 2011 and March 2012. This 15% has proved difficult to attain so the HFEA prolonged this target until October 2012 when it was reassessed.

3) all clinics are responsible for devising a 'multiple pregnancy minimisation strategy' to lower their rates (HFEA 2012). The 10% maximum multiple births rate

came into effect on 1st October 2012. This means no more than 10% of a centre's annual birth events, from treatment started on or after 1 October 2012, should be multiple births. Births from IVF, ICSI and GIFT treatments using fresh and frozen embryos/eggs, from patients' own eggs and donor eggs are included in this multiple birth rate. Births from IUI or DI are excluded (HFEA 2013).

According to data collected by the Multiple Births Foundation in the UK the twinning rate per 1000 pregnancies in the population as a whole stayed stable during 2000 and 2005 with a rate of 14.24 and 14.72 respectively. The triplet rate per 1000 pregnancies has dropped significantly from 0.42 in 2000 to 0.22 in 2005 (Multiple Births Foundation 2005). Interestingly, the triplet rate in the UK peaked in 2001 and started to drop in 2002 coinciding with the new policy introduced by the HFEA restricting transfers from 3 to 2 embryos in women under 40. The overall multiple birth rate per 1000 pregnancies increased slightly from 2000- 2005: 14.67 and 14.94 respectively. The most current statistics show figures of 15.48 for 2008, 16.3 for 2009 and 16.1 for 2011 (Office of National Statistics 2013). These figures demonstrate that despite fairly sophisticated policy in the UK up until 2009 that attempted to reduce the overall IVF multiple birth rate by limiting many IVF transfers to two embryos, decreases are only apparent in the triplet birth rate. This is commendable because a triplet pregnancy places the most risk on the mother, babies and health care system. However the twin and overall multiple birth rate figures continue to rise. This suggests the need for new public policy measures. These were indeed introduced in 2009 by HFEA and are still continuing to be implemented.

### 1.2.2 Non-Regulation

In an effort to understand more about IVF and multiple births this project looks at data and other information from clinics in the UK, and other countries in Europe where legislation governs IVF, and situates these clinics globally where data are available. Information from a global analysis of IVF provision may be helpful in an analysis of methods to contribute towards the HFEA's policy of reducing multiple births by adopting SET. Some countries such as Belgium and Sweden have been



very successful at limiting these births and others such as the United States and much of Eastern Europe have not.

### 1.2.3 Patient Support and Regulation

Many studies support the notion that the outcome of infertility treatment may be influenced by psychological factors. A number of studies have examined stress and mood state as predictors of outcome in IVF. The majority of these studies support the hypothesis that distress is associated with lower pregnancy rates among women pursuing infertility treatment (Boivin 1995, Thiering 1993, Demytenaere 1998, Smeenk 2001, Sanders and Bruce 1999). As a background for the research for this project I was an attendee at various fertility support groups. During these groups patients cited concerns about the clinic they attended and the treatment if offered. The most commonly cited concern was a lack of support services; little information available about procedures and a lack of transparency about the treatment processes themselves. In the UK support for fertility patients is a public policy issue. The government requires every clinic to offer a minimum level of counselling to certain types of patients. This is clarified to each clinic in the UK through the publication of the HFEA's Code of Practice. My research looks at the types of support clinics in the UK are offering patients to decrease distress and see if support mechanisms are, in any way, incorporating government mandates to decrease the multiple birth rate at UK clinics. One policy response to the problem of multiple births and IVF could be through the promotion of counselling in the IVF clinic. If counselling is fully integrated into each clinic, it has the potential to serve as an important tool to promote SET as a forum to discuss and inform a patient of the benefits of a single pregnancy. Resistance to SET can be explored and complications surrounding multiple embryo transfer clarified. When educated comprehensively and prepared fully for any potential SET treatment a patient will have the tools to make the decision to embark upon the treatment with greater confidence. Secondly, it is possible that counselling may help to maximise the chances of successful implantation of the single embryo by acting a mechanism to reduce stress and distress surrounding the procedure and therefore negating the necessity of implanting multiple embryos.

## CHAPTER TWO

### BACKGROUND: AN OVERVIEW OF IVF

This chapter provides a basic understanding of IVF and introduces some of the current issues surrounding this technology and some of the driving forces behind its development.

IVF is the most widely used of all assisted reproductive technologies. In the UK 12,589 babies were born as a result of IVF treatment in 2006. There were 12,714 babies born in 2009 as a result of IVF treatment using women's own fresh eggs. 2,441 of these were born as a multiple. More recent figures reveal that there was a six percent rise for 2011 in the number of fertility treatments carried out in the UK, according to the HFEA. The HFEA's annual report, which was released on 16 November 2011, shows that 45,264 women received fertility treatment in the UK in 2010, compared to 42,593 in 2009. This equates to 57,652 cycles of both IVF and ICSI in 2010 – an increase of 5.9 percent on the previous year (HFEA 2011).

A justification often given for the high use of IVF in the UK is women's later childbearing. In England and Wales the average age of married mothers at childbirth has increased by three years since 1971, rising from 26.2 years to 29.1 years in 2000. In 2006 the mean age for giving birth rose to 29.2 years (Office for National Statistics 2007). Recent figures from the HFEA's November 2011 annual report reveal that the average age of women undergoing IVF in 2010 was 35.1 years, up from 33.6 in 1991. The majority of women were aged 37 years or under, with thirty percent aged between 38 and 42, four percent between 43 and 44 and only around two percent of cycles were to women aged 45 and over (HFEA 2011).

In the UK, infertility is defined as 'failing to get pregnant after two years of regular unprotected sex' by the National Institute for Health and Clinical Excellence (NICE). It is the most common reason for women aged 20-45 to see their GP, after pregnancy itself and is estimated to affect around one in six couples (HFEA 2008).

Also, women may use IVF if they decide to have children alone or are living in a same-sex relationship. Other reasons for an increased demand for IVF include an increase in sexually transmitted diseases affecting fertility (Santelli 2009), and the fall in the number of children available for adoption (Office for National Statistics 2009). A study carried out by the Economic and Social Research Council (ESRC) Centre for Population Change at the University of Southampton indicates that in the UK many women are having children almost two years beyond the point they anticipated while an intended family size of at least two children has not, on average, proved a reality (Berrington *et al.* 2014). Research concludes that this gap can be attributed to increasing numbers of women taking on careers as a result of increased educational opportunities, households not being able to afford large families or just not being able to find the right partner. Between 1991 and 2007, the research asked women how many children they intended to have and found they consistently gave a higher rate than the actual average fertility rate throughout that period. The intended family size ranged between 2.0 and 2.16 children per woman when the actual fertility rate was around 0.3-0.4 children per woman lower until 2001, after which the gap narrowed slightly. Women also expected, on average, to have their first child at a younger age than actually proved to be the case. Those aged 22-25 in 1991/94 expected to give birth within 3.9 years – the actual average wait was 4.5 years. For women aged 30-33, the anticipated two-year wait for a first child became 3.5 years on average. Overall, the figures revealed there was a degree of uncertainty about reproduction decisions for women throughout their childbearing years, including a significant minority of women who did not make firm decisions about future childbearing. The report concludes with suggestions that the gap could be due to "change with age due to learning, altered preferences associated with the experience of childbearing, competition with other activities, retrospective rationalisation and a variety of constraints including fecundity, housing, economic factors, difficulties in partnership formation, partner preferences, as well as period influences" Of particular interest are the significant number of women who have postponed childbearing into their thirties and who continue to intend to start a family. Data from this study suggested that only around half would manage to do so in the subsequent six years. Further research is required to investigate the extent to which those who did not achieve a

birth (the perpetual postponers) were unable to for biological reasons as opposed to social or economic constraints. Whilst level of education is strongly correlated with the intention to start a family among older women, no educational differences in the likelihood of actually having a child are seen. Instead, it is women in the top earnings quartile who have postponed childbearing into their thirties who are the most likely to have a child at older ages (Berrington 2004).

The history of IVF began in the animal breeding industry where techniques were developed to create physically superior and more fertile animals for human use and consumption (Hansen 2006). The methods have been transferred to women as a solution for infertility. However, IVF is not a cure for infertility, it merely circumvents the infertility and in some cases, a baby is produced. The man or woman is still infertile after the procedure. Louise Brown was the first child born as a result of IVF. She was born in the UK on 25th July 1978.

## 2.1 The Process of IVF

The clinical procedure of IVF involves 5 steps, each is interconnected and dependent upon successful completion of the prior procedure. The steps can be broken down into the following and will be explained shortly: 1) ovulation stimulation, 2) collecting or harvesting of the eggs, 3) collecting the sperm, 4) fertilising of the eggs and embryo incubating, and 5) Implanting of the embryo/zygote.

Before any of these steps are attempted, the woman or man seeking treatment may be first diagnosed as infertile according to the definition of fertility utilised by an individual clinic or hospital. This may not be relevant for single women, surrogates and lesbian couples. In the UK infertility is defined as 'failing to get pregnant after two years of regular unprotected sex' by the National Institute for Health and Clinical Excellence (NICE). Also, being accepted into an IVF programme may require a number of additional criteria to be met, again determined by the hospital or clinic. For example, age restrictions are sometimes

applied. In the UK the IVF clinic has a statutory duty to take account of the welfare of any resulting or affected child.

## 2.2 Costs of Treatment

The costs of IVF are very great so also become a factor for deciding who is able to utilise the technology. Thousands of pounds are spent in order to create a child through IVF. The typical cost of a cycle of IVF alone in the UK is £5 000 (NHS 2011). This figure varies, depending on the consultations, drugs and tests that may be required for the treatment. Procedures such as embryo freezing may also be charged separately. In the UK this may be partially funded by the government and the extent of IVF treatment available to any individual is determined by residential location as local health bodies apply their own eligibility criteria. The Government has said that, from 1st April 2005, all women with appropriate clinical need should have at least 1 cycle of treatment paid for by the NHS. The National Institute for Clinical Excellence (NICE) guidelines suggest that couples should be offered up to 3 cycles of IVF on the NHS if the woman is aged 23-39 years and the couple has an identified cause for their infertility, or have not conceived after 3 years. In May of 2012 NICE updated these guidelines. One key new recommendation is an increase in the upper age limit from 39 to 42 for women where IVF is the only possible route to pregnancy. These women should be offered one full cycle of IVF. Also, the lower age limit of 23 has been removed. NICE recommend that it is appropriate to fund IVF treatment when the chances of success are more than 10% (NICE 2012). Currently the Department of Health's expert group on commissioning NHS fertility provision is looking at the barriers to the implementation of the NICE fertility guideline. The most recent report about this issue was published in July 2011 by UK politicians who found widespread inconsistencies in the provision of fertility treatment by the NHS. The report published by the All Party Parliamentary Group (APPG) on infertility, used freedom of information requests to gather data from 177 Primary Care Trusts (PCTs) or the equivalent in the area. At the time the data were gathered, around a quarter of the 171 respondents offered the full three cycles of IVF recommended by the National Institute for Health and Clinical Excellence (NICE), with five PCTs providing no

fertility treatment whatsoever. Many PCTs used age 35 as a cut off, not 39 as recommended by NICE, others used additional restrictions such as weight and smoking to restrict treatment and some clearly denied infertility to be a physical disease in need of NHS treatment (APPG 2011).

The denial of infertility as a disease is prolific in primary care trusts across the UK. This is despite the fact that on 30 November 2009 The World Health Organisation (WHO), in conjunction with the International Committee for Monitoring Assisted Reproductive Technologies (ICMART) formally recognised infertility as a disease in its new international glossary of ART terminology. The jointly prepared glossary appeared simultaneously in journals *Fertility and Sterility* and *Human Reproduction*. According to the glossary, the definition of infertility is 'a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse' (World Health Organisation 2009). This differs from the definition offered by NICE (see p.29).

A study looking at the economic costs and consequences of ART has concluded that governments reap long-term economic benefits from funding ART services. The European Society of Human Reproduction and Embryology (ESHRE) Infertility and Society Task Force, who published the report, found that how ART treatment is funded and subsidised is an important control on its use, treatment choices available, embryo transfer practices and, ultimately, multiple birth rates. The authors report that governments receive the equivalent of an eight-fold return on investment 30 years after a child conceived by IVF enters the workforce, given it costs approximately €15,000 to conceive an IVF child. The authors argue that this high estimated return on investment for ART children could mean it makes good clinical and economic sense to provide affordable treatment for those who need it. Cost influences consumer behaviour. The authors found that patients lacking financial support often sought cross-border reproductive treatment in countries with cheaper or less restrictive services than those in their native country. The risks of this lie in potentially lower standards of care and less responsible embryo transfer practices (Connolly 2010).

The yearly increases in demand for IVF mean that there is a mismatch between patients' expectations and resources available. Currently data collected by the HFEA demonstrate that in the UK 60% of all IVF patients pay for their treatment privately (HFEA 2012). One solution may be to means test IVF so that couples that really need fertility treatment without financial means can have access to it. While there is still a severe lack of NHS funding for fertility treatment it is understandable that some couples are willing to take the risk of a multiple pregnancy and request more than one embryo to be implanted during their IVF cycle. Patients who receive no NHS funding and can only afford to pay for one private cycle may be willing to risk twins or even triplets to allow them to have the family they so desperately want. In countries where single embryo transfer is the norm, such as Belgium and Denmark, couples are entitled to six and five free cycles of IVF respectively (van Montfoort 2005).

Research undertaken in 2008 by the Fetal Medicine Unit at University College London Hospital (UCLH) makes a link between higher order multiple pregnancies (triplets and above) and the numbers of women travelling to other countries for fertility treatment. The ten-year study carried out in London showed that of the 94 women expecting three babies or more as a result of IVF treatment, 24 of them had received their treatment abroad. The women were treated in countries including Cyprus, Algeria, France, Germany, Belgium, Greece, India and Japan and were reported to be 18 per cent less likely than their UK-treated equivalents to opt for embryo reduction. The study also found that the extra care required by IVF twins and triplets cost the NHS £9,000 and £32,000 respectively (McKelvey 2009).

The first study on the strength and motivations behind the fertility tourism industry was an online study also conducted in 2008, by Infertility Network UK. It found that an overwhelming majority of infertility patients in the UK said they would contemplate travelling abroad for fertility treatment. Among the 339 infertile patients who responded to an online poll, 76 per cent stated they would be willing to seek fertility treatment outside the UK with 70 per cent citing that their reasons would be to avoid higher costs and long wait-lists at UK clinics (Infertility Network UK 2008).

In addition to this, there is evidence that lack of affordable treatment encourages patients and clinicians to opt for cheaper fertility treatments such as stimulated intrauterine insemination and ovulation stimulation. These often less regulated procedures have less controllable means of minimising multiple births (ESHRE 2010). Affordability is closely linked to the problem of multiple births and ART on a clinical level. Prior to tighter regulation in the UK affordability influenced clinical practice: the financial incentive to achieve pregnancy in a limited number of cycles lead to the transfer of multiple embryos. This is still apparent in countries with little or no regulation.

In the United States and the majority of Canadian provinces, the government does not cover the costs of infertility treatment, which forces would-be parents into private clinics. Some patients may have private insurance provision. In addition to fees for the regular IVF cycle there may be additional fees for donor eggs/sperm, storage of embryos and thawing and transferring them (Appendix 1). Furthermore, added expenses such as transportation and accommodation costs, if the couple travels a distance to seek treatment are a consideration. Additionally, while undergoing IVF, many women must cease employment due to the physical, emotional and time demands of the procedures. As a result of these factors, often, only financially secure couples are eligible for IVF. In the UK and France, where some IVF treatments are covered in the national health programme, figures indicate that the incidence of IVF per capita is five times that of North America (Wiscot, Meldrum, 1997:20). This indicates that there are probably many couples that would benefit from IVF who just cannot afford it. Currently the Nordic countries and Belgium offer the highest ART availability in terms of cycles per million population. In Belgium, Denmark, Finland, Iceland, Norway, Slovenia and Sweden more than 3.0% of all babies born were conceived by ART. By contrast the proportion in the USA - with 57,569 ART babies born - was estimated to be slightly more than 1% of total births (ESHRE 2013).



## IVF Procedure

The following pages outline the technical aspects of the IVF procedure as would be experienced by any patient receiving fertility treatment in an infertility clinic.

### 2.3 Ovulation Stimulation and Fertility Drugs

In order to collect eggs, the female must be superovulated by a 'hormone cocktail' that consists of GnRH (Gonadotropin releasing hormones), agonists, and antihypothalamic drugs. The GnRH agonists are employed through injection to suppress or shut down the normal menstrual cycle so that it does not interfere with the process of superovulation. Once superovulation occurs, women receive a second drug by daily injection. These menotropin drugs stimulate the ovaries to produce eggs through the use of natural follicle stimulation hormones (FSHs). The drugs stimulate the ovaries to produce multiple follicles. Follicles are fluid filled sacs in the ovary where the eggs grow. An egg may not be present in every follicle and no follicle contains more than one egg. Naturally a woman would only produce one egg per cycle. The injections contain drugs such as clomiphene citrate (commonly known as Clomid), menopausal gonadotropin (Pergonal), and human chorionic gonadotropin (Pregnyl) (London Health Sciences Centre, University Campus, 2002:1). Some women may get a mild reaction to the drugs such as headaches or nausea. A proportion of women who use these drugs will experience ovarian hyper-stimulation. A report for the HFEA in 2005, updated in 2008, found that severe ovarian hyper-stimulation syndrome occurs in approximately 1% of cycles (HFEA 2008). Symptoms include the enlargement of ovaries, vomiting, kidney failure, retention of fluid, accumulation of fluid in the body cavities, electrolyte imbalances, and in the most severe cases, development of blood clots and even death (Wisot and Meldrum, 1997:10).

The number of eggs produced may vary between 1 and 30. In general, the more eggs produced, the lower the average quality, so one does not benefit proportionally to number (Wisot and Meldrum 1997:124). Nonetheless, having

more eggs to fertilise supposedly increases the likelihood of successful fertilisation and outcome. This is because on average only 60% of eggs are capable of being fertilised. The use of hormones allows the doctor to attempt to control the woman's ovulation, but daily blood tests or urine tests to measure hormone levels along with transvaginal ultrasound scanning are used to monitor the ovulatory cycle closely so that eggs can be collected at the proper moment. A final medication called HGG (Human Chorionic Gonadotropin) is then given in a single injection to complete maturation of the eggs. Hormones will affect the patient both physically and mentally. Daily tests require the woman to take daily trips to the medical office. One clinic I visited in North America operated on a drop-in basis and it was not uncommon of women to wait 2-3 hours daily for monitoring.

#### Complications Surrounding Ovulation Stimulation and Fertility Drugs

In April 2008 a report released by the European Society for Human Reproduction and Embryology (ESHRE) said that fertility treatments performed in the UK are among the most risky in Europe. The chances of prospective mothers developing serious complications are reportedly four times greater than in other European countries where a comparative number of fertility treatments are performed. The report referred to the figure of ovarian hyper-stimulation syndrome (OHSS) occurring in 1% of cycles and acknowledged that although this figure appears small it was considerably higher than some other European countries. According to the report, Britain has the highest level of OHSS, the most serious side effect of IVF treatment. ESHRE's statistics revealed that in 2003, Germany performed three times as many IVF cycles as the UK but the UK still had almost three times more cases of OHSS. In 2004, French clinics reportedly had an OHSS rate that was a quarter of British clinics despite performing twice as many IVF cycles (ESHRE 2004).

#### 2.4 Latest Research and Fertility Drugs

Latest research suggests a link between certain types of cancer in women and

fertility drugs. Other evidence suggests drugs may have effects on embryo development. This controversial research suggests risks are very low and drugs are not regulated. Currently in the UK and elsewhere side effects are considered an acceptable risk associated with undertaking of the treatment.

One study undertaken in 2008 discovered that women who use fertility drugs might be at increased risk of developing cancer of the uterus. Dr Ronit Calderon-Margalit and colleagues at Hadassah-Hebrew University in Jerusalem studied 15,000 women who gave birth 30 years ago. They found that those who used fertility drugs were more likely to develop uterine cancer (cancer of the womb), than women who had not used fertility drugs, but the risk was still low. Of 567 women who took fertility drugs, 5 had developed uterine cancer in the past 30 years, three times the incidence of women who had not used fertility drugs. For women who had used the drug Clomiphene, the risk was four times greater. The study, published in the *American Journal of Epidemiology*, also found smaller increases in the risk for other cancers: melanoma, breast cancer and non-Hodgkin's lymphoma (Calderon-Margalit *et al.* 2009).

The latest investigation into fertility drugs and health side effects for the recipients is a clinical study from the Netherlands. It demonstrates that women who undergo IVF treatment have an increased risk of developing borderline, non-fatal ovarian tumours. In this research, IVF-treated women were almost twice as likely to be diagnosed with this kind of cancer in later life compared with subfertile women whose ovaries are not exposed to the stimulation required as part of the fertility treatment. However, the researchers were keen to point out that the overall risk of getting any kind of ovarian cancer after IVF treatment remains very low, at just 0.71 percent, compared with 0.45 percent in women among the general population (Van Leeuwen 2011).

Another recent European study reveals that ovulator drugs, which result in ovarian stimulation in women, aged over 35 led to increased chromosomal abnormalities within the embryos they are seeking to create (Campbell *et al.* 2013). Genetic screening shows that the production of oocytes is disrupted during fertility

treatment involving ovarian stimulation. This process uses hormones to promote the release of a greater number of oocytes than normal and, in general, larger doses are given to women over 35, who need more help producing eggs. This research shows it can lead to abnormal chromosomal copy numbers, a condition known as aneuploidy. This is detrimental to both conception and fetal development, and can result in the failure of IVF, miscarriage and disorders such as Down's syndrome (where there are three copies of chromosome 21). Immediately prior to ovulation and subsequently following fertilisation, healthy oocytes go through two phases of a special kind of cell division called meiosis. Successful meiosis requires chromosomes to separate from each other at the correct time. During each phase small cells called polar bodies are produced, which when analysed can provide an insight into the chromosomal make-up of the eggs. Researchers from nine countries, including the UK, screened the polar bodies of 34 women aged between 33 and 40, who were undergoing IVF with ovarian stimulation (Campbell *et al.* 2013).

## 2.5 Fertilisation

Information detailing the exact sequence of the technical procedures surrounding IVF is available from an HFEA source called 'IVF- About IVF'. This resource is referred to in the following sections regarding egg and sperm collection.

### Embryo Creation

For in vitro fertilisation to occur, the eggs are taken from the incubator and placed in separate petri dishes to which high concentrations of sperm are added to the eggs approximately 4-12 hours after the retrieval. These are then put into the incubator once again to facilitate fertilisation. An examination of each egg within 20 hours determines whether they have been fertilised. Each egg successfully fertilised by a single sperm results in an embryo. The remaining fluid from the follicles and cells not used for IVF is discarded according to the clinic's guidelines. Alternatively, the couple may have opted to donate them to be used for quality

control procedures. Sometimes, the sperm are not capable of penetrating the egg and in these cases, the sperm can be injected directly into the egg via a fine needle or the egg's outer layer, the zone, can be drilled to allow sperm to enter the egg. This procedure is known as Intracytoplasmic Sperm Injection (ICSI). It may provide men who produce very small amounts of weak sperm a chance to achieve a pregnancy. Research from Australia has recently stressed that there may be a higher risk of birth defects for parents using ICSI when compared to natural conception. In 2012 this study concluded that these defects could be up to 57% increased compared to natural conception. This is because sperm are artificially injected that would not regularly naturally have the ability to fertilise an egg. It is thought that ICSI may be promoted in clinics as it offers a slightly higher success rate than natural IVF and may also increase clinic income as a result of the additional fee obtained for it. This has resulted in it being recommended for those patients that fall outside the category in absolute need of its benefits (Davies 2012).

The embryos will usually have divided into approximately 8 cells within 72 hours and will be ready for transfer. IVF often uses donor eggs, especially for older women. If successful, the resulting birth is a child who is not biologically related to the gestational mother. Since the start of this project studies are in progress to improve the culture that the embryos are kept in whilst in the laboratory so that they can be implanted at a more developed stage (blastocyst stage). This means that the embryos have developed for five to six days. This would improve their chance of implantation (Barrett, 2002). Currently most clinics in the UK and North America offer blastocyst transfer to suitable patients. There is a risk that the embryo may not develop in vitro after day 4 so the treatment is not recommended to all patients. In the UK an embryologist will advise on a case to case basis if it is safer to consider a 2 to 3 day embryo transfer than risk having no blastocyst to transfer on day 5/6 (HFEA 2011).

It is thought that only about 1 in 5 embryos are capable of being a baby (Winston, 1999:12). Some of the embryos may fail to develop properly. A good embryo has clear cells of relatively equal size and shape with one nucleus. The cells of a poor

embryo may have several nuclei, are often of unequal size and uneven shape and may be fragmented (Bonnicksen 1989:50). These abnormal embryos are discarded in compliance with clinic regulations (Lacey 2007). 'Good' embryos are implanted and if many embryos exist a decision regarding what to do with the 'extras' must be made. Spare embryos are usually frozen which allows them to be used at a later date. Approximately 70% of embryos will survive the process of freezing and thawing (Wiscot and Meldrum, 1997:144). Hence, fraternal twins that were once created naturally in a woman's body when separate eggs were fertilised at the same time can now be created in a laboratory, gestated and birthed years apart. Currently there are no studies to confirm any detrimental effects on the health of children born as a result of freezing embryos. However, freezing does detrimentally affect embryo quality and because of the loss of embryos during freeze/thawing during frozen embryo cycles, every effort should be made to attempt a fresh transfer (Selik 1995). New evidence presented on 6th January 2012 at the British Fertility Society Annual meeting suggests that babies born from frozen embryos have a higher birth weight than fresh embryos. It is speculated that this is due to an adverse uterine environment as a result of hormone stimulation for fresh embryos. Another speculation is that only large robust embryos are capable of surviving the freezing process. More research into short and long term effects is needed (British Fertility Society 2012).

Transfer to the woman's body involves passing a fine catheter loaded with the embryo(s) through the cervix into the uterus. Gentle pressure to a syringe, attached to the end of a catheter, transfers the embryo(s) into the uterus. This procedure requires no anaesthetic or medication. After the transfer, the woman must now wait to find out if she becomes pregnant. The earliest a pregnancy can be detected by blood test is the 12th to 14th day after transfer. Emotionally and psychologically, it can be a very difficult time in fertility treatment. If the test is negative the entire cycle must be started again or the patient may opt to leave the programme.

## 2.6 IVF and Technical Advances.

In the UK, Winston is a prominent campaigner for ethical administration of fertility treatment. At the time I started this investigation, Winston appeared regularly with a high profile in the popular media in the UK, to inform, stimulate debate and educate the public about ART. In his popular publications, Lord Winston advocates single embryo transfer. He frequently details adjuncts and improvements to IVF.

Winston advocates natural IVF because using the monthly produced egg of the patient avoids the issue of ovulatory hyperstimulation and its associated risks. This method also avoids the production of 'excess embryos' with the associated legal, ethical and social issues that they raise. The culture that the embryos develop in whilst in the dish could also be improved. Presently embryos are transferred 2 to 3 days after fertilisation (cleaved embryo transfer). Theoretically, the best time to transfer is 5 or 6 days after fertilisation (blastocyst transfer). Present IVF culture systems are not efficient to provide an ideal environment for this development.

Winston feels that it is worthwhile to pursue research in this area (Winston 1999). Since the time of publication advanced culture media have been available that can yield high blastocyst formation rates and blastocyst transfer has become commonplace. This has not happened however, as Winston recommends in conjunction with natural IVF (using the women's monthly produced egg) but with the use of fertility drugs to create multiple eggs for retrieval. Latest culture innovations studied by the university of Michigan suggest improved success rates using a bed of pulsating nails rather than static petri dish culture. Movement more closely imitates the environment of the womb, which is subjected to constant muscular contractions. However more follow-ups of the pregnancies resulting from this technique are needed (Hamzelou 2011).

Scientists at Oxford University have undertaken the latest research in science involving the health of embryos prior to transfer. They have developed a test that may help to improve IVF success rates by checking the health of embryos. The team, led by Dr Dagan Wells, has developed a test, which checks embryos during IVF for abnormal numbers of chromosomes. They tested a few cells taken from early human embryos, each of which should contain 23 pairs of chromosomes.

With more or less than this, embryos can fail to develop normally. They then looked at other properties of the cells, which had abnormal chromosome numbers. They saw changes in the lengths of telomeres, regions of DNA at the ends of chromosomes, and in the number of mitochondria, structures that provide a cell with energy. The scientists suggest that the length of telomeres and number of mitochondria could be new indicators that could help to select healthy embryos during IVF. The hope would be that these embryos are more likely to implant successfully and survive to term. "I think it offers the possibility of enhancing success rates of IVF, allowing couples to get to the point of having a baby more rapidly with fewer cycles, and avoiding the heartbreak of miscarriage or terminating a pregnancy because of serious disorders", said Dr Wells at the American Society for Reproductive Medicine's annual conference on 24<sup>th</sup> October 2011 (Wells *et al.* 2013). More still needs to be done to ensure that it is an effective method of predicting embryo viability, and it would have to go through clinical trials before it could be used in patients. In particular, adequate funding must be made available to allow this new technique to be assessed fully before it enters clinical practice.

Researchers at the CARE clinic in Nottingham, UK (part of CARE Fertility Group Limited and thought to be the largest independent provider of IVF in the UK) are using a new test to discover chromosomal abnormalities in a blastocyst prior to implantation. The test extracts cells for the part of the blastocyst that will develop only to be the placenta, the blastocoele and not the cells of the potential baby. During the test, a biopsy is taken from a five-day old embryo to examine whether it has two copies of all 23 chromosomes. Almost half the embryos resulting from IVF are aneuploid, meaning they have too many or too few chromosomes. Implantation of such embryos could lead to the development of various genetic conditions or spontaneous abortion. Only those with the exact set of 46 chromosomes are selected for use in IVF after the test. It is thought the screening test will cost an additional £1,000 to £2,000 in addition to standard IVF costs. Chromosomal abnormalities are the largest cause of miscarriages, accounting for over 50 percent of embryos that abort spontaneously in the first trimester. Using this technique can screen blastocysts for viability (Fischel *et al.* 2011).



Also, rhythmic activity detected in newly fertilised mouse eggs may provide a novel and non-invasive screening method for identifying embryos most likely to survive a full-term pregnancy, according to research published in Nature Communications. Researchers at the Universities of Oxford and Cambridge discovered that when a sperm enters an egg the cytoplasm begins to vibrate in a characteristic pattern, which can be used to predict the embryo's survival once implanted into the womb. According to the research the pattern of the sperm's early movements is predictive of whether the embryo will have successful developments throughout the entire pregnancy (Ajduk 2011).

With the recent successes in oocyte vitrification and storage, clear metrics are needed to determine oocyte as well as embryo quality prior to fertilising. It has been discovered that women with poor egg (or oocyte) quality could double their chance of becoming pregnant through IVF if given melatonin. The work was presented at the World Congress of Fertility and Sterility in Munich on 20 September 2010. A group led by Associate Professor Hiroshi Tamura (Yamaguchi University Graduate School of Medicine, Japan) measured the presence of the oxidizing agent 8-OHdG in follicular fluids. High levels of oxidising agents such as 8-OHdG is an indicator of poor egg quality. The group found that as melatonin concentration in the follicular fluids naturally increased, the level of 8-OHdG went down, leading the group to believe that melatonin was linked to the reduction of the stressing oxidising agents. Melatonin has known anti-oxidizing effects (Tamura *et al.* 2012).

Currently, embryos created through IVF are evaluated for developmental potential by morphology, a criterion lacking in quantification and accuracy. Some research has investigated the use of Polar Bodies to evaluate embryos. The results show that human Polar Bodies reflect the oocyte transcript profile, and suggest that genetic information detection and quantification through high-throughput laboratory techniques could result in the first molecular diagnostic for gene expression in certain oocytes. This could allow for both oocyte ranking and embryo preferences

in IVF applications (Reich 2011).

In December 2009 developments in fertility research in the UK were discussed at the British Andrology Society's annual conference in Belfast. The conference organiser, Professor Sheena Lewis from Queens University, Belfast, also highlighted the lack of funding going into fertility research in the UK. 'Research councils or charities across the UK spend less than one per cent of their income on reproductive research compared with nine per cent on cardiovascular and 27 per cent on cancer studies,' she said. She went on to say that 'research into infertility has not been deemed strategic to health services or governments over the past three decades and so had been dogged by lack of funding,' adding: 'Male infertility is now a public health issue. Infertility affects one in six couples around Europe and the male partner is responsible for 40 per cent of these problems.' She explained that DNA damage to sperm is a major cause of male infertility. Sperm DNA can be damaged by lifestyle factors such as smoking, alcohol, drugs and obesity. 'We are trying to develop diagnostic tests to give couples more information about the causes of their infertility and how to improve their chances of a successful conception,' she said, adding: 'We need to do this through multi-centred trials and this can only be done with increased government funding.' Over the past 50 years birth rates have declined in Europe, to 1.5 births per woman. In order to maintain population replacement, 2.1 children per couple is necessary. In 2008 the European Parliament acknowledged for the first time that falling fertility rates were a major cause of demographic decline (Cranage 2009).

## 2.7 Success Rates

With any technology or medical procedure it is important to know the success of the procedure. With IVF, this knowledge is difficult to determine as statistics are sometimes manipulated by reporting clinics, standardised records are often not kept at all, and the term 'success' often encompasses more than the measure of live births. Some IVF doctors and clinics have reported success rates as high as 50 percent (Brownlee, 1996:151). But in some countries there has often been little uniformity in what the statistics are actually measuring. Success rates may include

such things as ectopic pregnancies (the chances of having an ectopic pregnancy seem to be slightly higher in women having fertility treatment than those with a natural pregnancy and do not come to term), pregnancies which do not result in live births due to miscarriages or spontaneous abortions, and even only 'chemical changes' which may or may not indicate a pregnancy (Rowland, 1992:44).

Because clinics are competing against each other for patients, having higher success rates than their competitors makes them appear better qualified to handle the IVF procedures. This is one reason that some clinics and hospitals use various non-standardised criteria to measure their 'success'.

The most relevant data can be found where live birth rates per treatment cycle are reported. These figures can be found for clinics in the UK. The data show the live birth rate per embryo transfer and are published by the HFEA. Similar, yet less comprehensive, data for the US may also be obtained from the National Centre for Chronic Disease Prevention and Health Promotion. Its figures show live births per IVF cycle. At the start of this project I was looking at data from clinics in the 1990's. At that time different sources for my research quoted various live birth rates for IVF: averages of 19% were reported by the American Society of Reproductive Medicine for women under 39 and only 6.6% for women over 40; in Britain, women with blocked fallopian tubes undergoing IVF experienced a 10% chance of delivering a baby, 8.5% of women undergoing IVF in Australia gave birth; and in Canada, patients have met with quoted success rates ranging from 10 to 26 percent (Brownlee, 1996:151; Canada, Royal Commission, 1993:520,539; Rowland, 1992:46). In one study it was found that as women underwent increased numbers of IVF attempts, their chance of success decreased from a high of 13 percent on the first attempt to a low of 4.3% of the fourth attempt (Kaplan quoted in Brownlee, 1996:152). The natural fertility rate for an average couple under 40 years of age is a 18% chance of conception when having reasonably regular intercourse over a one year time period (Winston, 1999:102).

Since 1990 there have been increasingly sophisticated recording techniques in the UK and the US. The HFEA has been able to predict a 'National Average' success rate and this is compared to each clinic's actual success rate. In 2010 the national

average rates for 'Live births per treatment cycle' were: 32.2% in women under 35, 27.7% in women 35-37, 20.8% in women 38-39, 13.6% in women 40-42, 5.0% in women 43-44 and 1.9% in women over 44 years of age (HFEA 2010). In the US, The Society for Reproductive Medicine (SART) show national averages for 'Live births per treatment cycle' for 2008 to be 41.3% for women under 35, 31.1% for those 35-37 years old and 22.2% for women 38-40, with a 12.3% chance of success in the 41-42 age group (SART 2010). Improvements in success rates in the last decade may be as a result of a myriad of factors, including improvement in culture which allow embryos to reach the blastocyst stage before implantation and the more prolific use of ICSI and assisted hatching (whereby a hole is drilled into the embryo to assist implantation).

## **2.8 Some Criticisms of IVF Technology**

### **2.8.1 Fertility Drugs**

IVF clinics demonstrate a union between the medics, medicine and the marketplace. The clinic can quickly gain status and reverence in the business of producing new lives. Bolstered by the unique authority of the institute of medicine and the established status of clinical judgement, clinicians are well placed to shape the context in which they practice (Kerr *et al.* 1997). Economic supply and demand combined with human rhetoric allows the clinic to promote 'efficient' IVF services in both public and private domains and influence government policy, industrial investment and media attention. There are tremendous economic and commercial interests for those involved with creating, supplying, and delivering the services associated with IVF. These interests push the expansion of IVF as an acceptable method of conception. Fertility drugs used to stimulate the woman's ovaries and to allow the doctor control over the women's natural processes are big business and generate large profits. The transnational drug company, the Ares-Serono Group is the biggest producer of drugs used for ovulation stimulation. In 1991, when I started this research, the company sold 625 million dollars (US) of infertility drugs worldwide (Cameron 1996:110). In the literature that I read surrounding fertility drugs writers pointed to the fact that pharmaceutical companies, which

manufacture such drugs, very often also fund research to develop IVF technologies. Then they aggressively market the technologies through the unregulated infertility clinics in North America. The technology becomes institutionalised with a team of medical specialists who develop their own economic interests and a whole new norm for pregnancy is established.

This has been demonstrated in the pregnancy of the ‘Octomum’ in the United States. In a British television documentary the consequences of the chaos that had developed from this unregulated fertility treatment was evident. As was the unquenchable patient's desire to have as many children as possible at enormous cost to many individuals. Dr Kamrava, the fertility specialist who treated Nadya, has been expelled by the American Society for Reproductive Medicine. Nadya's relationship with her mother has irretrievably broken down. Many Americans have vilified her, saying that she has only done this for the publicity and to make money. She has been demonised on the Internet, with consequent issues for her older children who can now watch online the mainly unpleasant criticism of their mother. Her daily costs were huge and unemployed meant that she has to court and keep the media on side so that they pay her for every photo and story, for the survival of these 14 children, their food, their nappies (\$700 a week) and the hired help (\$10,000 a month). Consequently she also had to fight in court to control the money that she is given for the children as the local authorities wanted to put the money into a trust administered by someone else (Dunlop 2009).

It would appear that pharmaceutical companies that manufacture ovulatory drugs are the stimulus and power behind IVF as a service. This is paradoxical because it is questionable whether these drugs should be used at all in the process of IVF. Drugs for stimulating ovulation are reported to cause numerous side effects. These may include: multiple pregnancies, ectopic pregnancy, tubal lesions, endometriosis, ovarian cysts, weight gain, asthenia, pelvic pain, abdominal distension, nausea, hot flushes, vertigo, vomiting, headaches, blurred vision and mammary discomfort. One study indicates a 27 times increase in ovarian cancer among women who have taken fertility drugs who did not become pregnant. There was a two-fold increase among women who did become pregnant (Basen *et al.*

1993:184). The sociological literature that I read repeatedly reflected opinions that the medical industries manufacturing fertility medicine were all looking towards sensational market expansion. Speaking at the 6th World congress of IVF in Jerusalem in 1989, Canadian IVF specialist Dr. Bernard Lunenfeld estimated that at that time the potential market in the industrialised world for ovulation stimulatory drugs amounted to 10 million women, joined every year thereafter by an additional 700,000. At that time, 24 years ago, one cycle of fertility drugs cost the patient \$3000 (US), not including the cost of IVF. Women routinely do 3 cycles; 6 cycles are frequent and 10 not unusual. The profits from these drugs are staggering (Basen *et al.* 1993:186) and increase considerably every year. Now, in 2013 IVF technologies appeal to a large global mass market. However, It appears little research is done into the harmful effects of these drugs and no one involved in the process of IVF has an interest in curbing their use.

### 2.8.2 Respect for the embryo

A different critical perspective of IVF is that it is a tool that fundamentally tampers with the roots of human identity (Iglesias 1999). This type of discussion is important yet sometimes ignored because of the publicly accepted, widespread use of IVF as a fertility treatment. In her work, medical ethicist, Iglesias, makes an emotional plea about how detrimental to the 'human family' IVF as a practice is. The Hippocratic oath as amended in October 1993, reads 'I will maintain the utmost respect for human life from the time of commencement'. Iglesias argues that IVF, with its limited success rate and inevitable loss of thousands of embryos, which are destroyed or die in the process, does not adhere to this principle. She states that each embryo must be considered a human being because within its total DNA conformation are DNA structures which determine, and are common to, the human species (Iglesias 1990:43). She concludes that "My general recommendation, based both on moral and social grounds, is that we should strive to encourage adoption rather than a generation of human beings by risky technological means which ultimately involve the direct destruction of some human

beings. We owe a living to those children already existing. We do not owe a living to those who have not yet come into existence"(Iglesias 1990:54).

Iglesias speaks with conviction as she discusses IVF as a tool that essentially tampers with the basis of human life. She does, however, fail to acknowledge that IVF is an established and publicly supported practice; as such it influences people's moral attitudes and is unlikely to just disappear. She argues against the utilitarian tradition of science, and Iglesias feels that embryos are not cared for or respected for their own intrinsic value. Science adopts every method technically available to achieve conception. She considers that the goal of science should be the promotion of the well being of every human being.

The overall message that Iglesias intends to impart on the reader is that any procedure that involves selecting embryos and destroying those that are unwanted or which have been used for research, for whatever end, is an affront to human life and dignity. In the UK between 1994 and 1998, over half of the total number of embryos created for use in IVF (in vitro fertilisation) have not been used, according to government statistics. Between 1991 and 2005, 1.2 million embryos were not used, from a total of more than two million embryos (2,137,924) created by specialists while assisting infertile couples in the UK to have babies (HFEA 2009). Unused embryos in clinics under UK law may by consent be discarded, frozen, donated to research or donated to other infertile couples. Viable embryos are often frozen for future use and must be destroyed within ten years. A smaller number than are frozen are donated to research: 82,955 of the 1.2 million. Embryo donation to infertile couples for adoption is rare and generally unpopular with donating and prospective parents who were initially motivated to endure medical intervention to have a biological child (Woolf: 2007). Consequently, thousands of embryos are destroyed or discarded each year (Harvard 2008).

From a religious perspective, Antony Fisher, a deacon of the Catholic Church with a background in humanities, gives a general discussion what he feels are the most critical issues surrounding IVF in Australia (Fisher 1989). Like North America, Australia also lacked a clear legislative framework to govern its practice. However,

since time of publication of 'The Critical Issues', many states in Australia have adopted professional standards and ethical guidelines. Fisher feels that this is because science and technology have far outpaced society, ethics and law. In Australia IVF has gained in popularity because of a decline in the number of adoptees. The use of contraception and abortion has risen. There is also a rise in the number of single and young mothers who want to keep their children due to changing social attitudes and better government support.

Fisher pays much attention to the problem of IVF and multiple pregnancies. In Australia around 2 in 5 IVF babies were twins, triplets, or more. Of 1, 851 live births in Australia in September 1987 using IVF, 750 were multiple pregnancies (Fisher 1989:36). This is said to be more than 30 times the normal rate. There is a high premature rate in this type of pregnancy. Most twins (54%), nearly all triplets (95%) and all quadruplets (100%) in Australia were born prematurely (Fisher 1989:38). Premature labour can be complicated and dangerous. Also, a high proportion of multiple transfers miscarry, and those that don't are often encouraged to have an induced abortion for some fetuses. Fisher also points out that infertile couples are often emotionally vulnerable, open to exploitation and are highly tolerant of painful and inconvenient procedures (Fisher 1989:88). This may mean that they are prescribed a multiple transfer for expediency without being fully informed of the consequences. This may result in a difficult multiple birth or a psychologically painful fetal reduction.

Fisher was critical of IVF practice at the time of publication. He portrays IVF as a biotechnological development that is in widespread use without society's judgment of whether it is ethical or desirable. A large part of this book is dedicated to arguments from various religious denominations. IVF is described as being inconsistent with the 'sanctity of life' ethic due to its reckless indifference to the fate of mass produced embryos. An underlying argument is that a community which values many other things above the life of an embryo or fetus will experience a gradual but significant erosion in its valuing of human life generally. It appears that the practice of IVF as described here is being conducted in a way that seems to be commodity orientated. A 'product' is developed in a way that depersonalises each



individual embryo.

Fisher exposes the reader to questions about the sanctity of life and the origins of human life. Different opinions exist with regard to these fundamental concepts. One international poll undertaken in November of 2008 has shown a range of opinions about when human life begins biologically. It came ahead of a proposed constitutional amendment in Colorado, US, which would have conferred legal rights to embryos at the point of fertilisation. Reproductive Biology Associates, an IVF clinic in Atlanta, Georgia, commissioned the poll. Respondents were asked when human life begins and given 12 answers, ticking the one they most agreed with. Overall, 23.5 per cent of voters selected detection of fetal heartbeat as the point when human life begins. Just fewer than 23 per cent selected fertilisation, and implantation of the embryo in the womb lining came third, with 15 per cent. Around 650 people were polled. The poll demonstrates the wide religious and geographic spread of opinion on when biological life begins. Roman Catholics had the highest proportion voting for 'sperm-egg' fusion, around 31 per cent. In contrast, a third of Jewish respondents, 29 per cent of agnostics and 27 per cent of Muslims opted for fetal heartbeat. Geographically, only 13 per cent of UK respondents opted for 'sperm-fusion', with 43 per cent choosing 'fetal heartbeat'. In contrast, 47 per cent of Australians voted for 'sperm-egg' and only 7 per cent for 'fetal heartbeat'. In North America 27 per cent choose 'sperm-egg', 24 per cent 'fetal heartbeat' and 18 per cent 'implantation' (Coghlan 2008).

### 2.8.3 Fetal Reduction

Fetal reduction is one of the most ethically contentious aspects of IVF. In his publication Lord Winston gives a clear explanation of the process of fetal reduction, which is offered to patients carrying a multiple pregnancy. Using an ultrasound probe a needle is passed into the uterus and introduced directly into the developing embryo where a compound, which is not toxic to the mother, may be injected into the heart of the developing embryo. This processes described as a form of feticide

which can be 'psychologically devastating' to the expectant mother. There is also a risk to the pregnancy and it is not uncommon for a pregnancy to miscarry after this procedure (Winston 1999). Winston is of the opinion that, an infertile patient desperate for children may conceive a large number of babies; consequently having to make a decision to have some of them killed and then lose the whole pregnancy. Serious guilt, sadness and depression may follow. Winston makes it clear that the risk of pregnancy loss following fetal and multifetal reduction is real and substantial (Winston, 1999:202). Additionally, transferring several embryos and then performing selective reduction is ethically questionable. The concern here is that a society that accepts such a practice may be susceptible to other widespread shifts in attitudes and values with respect to human life. Catholic teaching prohibits in vitro fertilization, maintaining that a child has the right to be conceived in the marital embrace of his parents, consequently, the practice of fetal reduction is condemned by the Catholic Church and by groups such as Planned Parenthood Inc. and the American Coalition of Life Activists (Fisher 1999).

Figures from the Department of Health show that in 2010, 85 women expecting multiple births opted to abort one or more fetuses while continuing with the pregnancy of at least one other. This is an increase from 59 women in 2006 (Kay 2012). The more complicated multiple pregnancies lie almost exclusively in the IVF domain. Of these 85 women, 51 reduced twins to a single baby, 20 reduced triplets to twins and nine women expecting triplets chose to give birth to one child. Five women gave birth to twins following pregnancy with four or five fetuses (Ogilvie 2013). I was unable to find more recent comprehensive nationwide data for selective reduction. However evidence suggests that fetal reduction for twin pregnancies is becoming more commonplace (Barratt 2010). One perspective is that the likelihood of taking home a baby is higher after reduction than remaining with twins and therefore it is proposed that twin-to-singleton reductions might be considered with appropriate constraints and safeguards (Evans 2004). It has been proven that early (less than 8 weeks), non potassium chloride methods of reduction are superior in terms of safety (Lee *et al.* 2008). An opposing view is that the imperative must be for health professionals to reduce the need for women to have to make these difficult choices in the first place and the emotional burdens

associated with such choices are avoidable (Barratt 2010, Ogilvie 2013). The differences in motivation for such procedures and emotional burdens surrounding and arising from them are not quantifiable and clear cut.

A pragmatic and more technically based account of fetal reduction can be found in a factsheet on the website of the ASRM. It states that multifetal pregnancy reduction usually takes place early in the pregnancy, within the first 12 weeks. A specialist performs the process and the patient can go home the day of the procedure. At 12 weeks in the pregnancy, the fetus is enclosed in a fluid-filled pouch, called a gestational sac. The specialist will inject a needle filled with a liquid, frequently potassium chloride, into the gestational sac of the target fetus. The liquid will stop fetal heart motion. After this procedure, 4% to 5% of women may miscarry all the fetuses. A patient is very unlikely to have an infection after this procedure. Even if a patient does have a multifetal pregnancy reduction, they are still at risk of going into labour and giving birth too early. The factsheet does still acknowledge that it is a hard decision to make, especially after using ART to achieve pregnancy (ASRM 2008).

It is clear that a comprehensive adherence to single embryo transfer and multiple birth reduction health policy in the UK can diminish reliance upon fetal reduction. Although clearly controversial in nature, fetal reduction was offered to me at the IVF unit where I conceived my children as a routine option in the event of a high order multiple gestation. Fetal reduction may also be controversial regarding the post-procedure outcome for the family. Follow-up studies to date are limited and confined to one year after reduction (McKinney, *et al.* 1995, Schreiner-Engel *et al.* 1995). Schreiner-Engel *et al.* report that acute feelings of emotional pain, stress and fear are experienced during this procedure and that mourning for the loss of the foetus or foetuses was reported to occur in 70%, but that most grieve for only a month. However, moderately severe sadness and guilt can persist for some “especially for an identifiable sub-group who were younger, more religious and who had viewed the multi-foetal pregnancy on ultrasonography more often” (Schreiner-Engel *et al.* 1995: 541). This study concluded that the majority were reconciled to a termination of some foetuses to preserve the lives of the remaining few. Again

the role of the counsellor or support team can be instrumental in recognising issues surrounding fetal reduction. They can provide a forum to discuss these sensitive issues and may also discuss with the partnership how they will deal with the possibility of telling the surviving child or children about the fetal reduction (McWhinnie 2000).

Research has attempted to monitor the physical and mental development of co-siblings surviving fetal reduction of multifetal pregnancies. These children were matched with controls for birth weight, gestational age, sex, mode of delivery, parity, age at examination and mother's age and education. The children's age at evaluation varied between 12.5 and 38 months. It was found that the mental and physical indices of these children did not differ from their matched controls (Brandes *et al.* 1990). Also a study has attempted to assess fetal safety during multifetal pregnancy reduction. The study followed women with triplet and higher-order multiple pregnancies on fetal loss, preterm birth, and perinatal and infant mortality and morbidity. From nonrandomized studies, multifetal pregnancy reduction appeared to be an effective treatment option; with outcomes comparable to those obtained from twin pregnancies conceived spontaneously or after assisted reproductive techniques (Dodd 2004). However it is important that parents are given information and counselling early in their pregnancy and that clear facts are presented early. This gives the parents time to make an informed decision based on their individual moral and religious values.

## **2.9 Regulations, Infertility and IVF in the UK**

**The UK is a global forerunner in the establishment of legislation and public policy to govern IVF. Currently this is overseen and administered by the often internationally revered HFEA. In recent years policy specifically addressing IVF and multiple births has been implemented by the HFEA. Currently this is in its final stages. Progress has been made, however policy has met with patient resistance and the final targets that IVF clinics are required to meet have not been achieved.**

### 2.9.1 IVF Policy Issues

In Britain, almost 30 years ago a committee was set up under the chairmanship of Baroness Mary Warnock in July 1984. Its report, titled the 'Report of the Committee of Inquiry into Fertilisation and Embryology', was subsequently published in 1985 with an introduction by Warnock titled 'A Question of Life'. The Human Fertilisation and Embryology Act 1990 was based on the recommendations from the issues surveyed by the Warnock Committee Report. Chapter five of the Warnock report discusses IVF. The subject of the number of embryos transferred is given consideration (5.4). After debate about the benefits and risk of transferring more than one embryo they conclude that 'This is a field where constant reassessment is needed as new evidence becomes available....and that in each individual case the number of embryos transferred must be a matter of clinical judgment on the part of the practitioner responsible for the woman's care'. It was recommended that patients give consent to numbers transferred and that the practitioner give consideration to social problems of a multiple birth, problems that may affect the continued well-being of the mother in looking after the children and may adversely affect the children themselves.

The report goes on to detail arguments against IVF. These are 1) the practice represents a deviation from normal intercourse and that the unitative and procreative aspects of sexual intercourse should not be separated (5.6). This argument, based on fundamental principles was deemed irrelevant for formulation of public policy. 2) IVF results in more embryos being brought into existence than will be transferred into the mother's uterus. It is morally unacceptable to allow them to die (5.7). In what appears to be a response to this debate the committee later held that embryos younger than two weeks old could not be regarded as 'individuals' (section 3 of the Act). This is because the first sign of organ formation occurs about 2 weeks after fertilisation. This obviously contradicts the view that the 'individual' exists at the time of conception. 3) Whether the country can afford such expensive treatment which benefits only a few, and whether money could not be 'better' spent, that is, with beneficial effects for more people, elsewhere (5.8). The committee felt that this criticism related to the extent of the provision not to

whether there should be any provision at all. Further, without provision there is no opportunity to evaluate costs and benefits and refine them so as to become more cost-effective. The priorities argument was therefore felt to be an argument for controlled development, not an argument against the technique itself. It was concluded that IVF was an acceptable means of treating infertility and the service should be available subject to licensing and inspection. It was recommended that IVF should be available and organised within the NHS.

Additionally, a regulatory authority, The HFEA was established in 1991, following the passing of the Act in 1990. It is a licensing authority that was provided for by the Act and was the first of its type in the world. In addition to the licensing of IVF centres, the HFEA is also responsible to provide information about its service to prospective patients. The Patients' Guide to DI and IVF Clinics gives advice to patients and encloses a breakdown of the results achieved by each clinic in the UK.

Through the HFEA, the Human Fertilisation and Embryology Act 1990 makes provisions to regulate and monitor treatment centres and ensure that research using human embryos is carried out in a responsible way. The Act is described as being 'probably the single most important piece of legislation any Government had brought forward in the last 20 years' (Morgan 1991: 1). Morgan's guide to the legislation explains how assisted reproduction has challenged old philosophies of families and family law. It is felt to be a response to the meltdown of the nuclear family, 'in less than ten years half of all children born in the United Kingdom will be brought up outside the 'conventional' family' (Morgan 1991:3). This is accompanied by the rise of a 'want' society where it is fashionable to seek the fulfilment of wants and accept less readily that some desires cannot, should not or even must not be fulfilled. Other, more specific suggested reasons for an increased concern over fertility are that women are choosing children later as a result of career mobility and a more socially acceptable desire to have children in a number of sequential relationships. There are fewer children available for adoption because of contraception, abortion and an improved welfare state. Medical advance has enabled physicians to offer sophisticated techniques of diagnosis and

treatment for infertility. This coupled with rising incomes allows the growing number of infertile couples to be heard by the medical profession and given fertility treatments specific to their condition. Lastly the media play a role in developing public opinion on issues of the family. There is a strong promotion of 'family' values on the political agenda. This has been firmly supported by the media. It makes a childless couple seem a deviation from society (Morgan 1991:4).

The Human Fertilisation and Embryology Act 1990 provided the apparatus to allow for guidelines to decrease the risk of multiple births for women using IVF. Section 25 of the legislation provides that the licensing authority maintain a published code of practice. This is to give guidance about the proper conduct of activities carried on under license. Failure to observe these codes may lead to revocation of a clinic's license. At the start of my research the published code of practice was the Fifth Edition, April 2001. It stated under section 9.18 that 'No more than, three embryos should be placed into a woman in any cycle regardless of the procedure used'. In February 2002 the HFEA revised this policy to state that no more than two embryos be transferred in any one cycle to women under 40 years of age using her own embryos and no more than three embryos if a woman is over 40 years of age using her own embryos. If donor embryos are used no more than two should be transferred regardless of the woman's age at the time of the transfer. This amendment was communicated to all licensed centres in the UK and was reflected in the 6th Edition Code of practice. Additionally, under direction of the legislation, the Minister of Health asked the Royal College of Obstetricians and Gynaecologists that consideration be given to issuing College guidelines pointing to the need for appropriate counselling about problems of multiple births prior to treatment and that measures should be taken to seek to avoid multiple births wherever possible (RCOG 2006).

The Human Fertilisation and Embryology Act 1990 has been amended by The Human Fertilisation and Embryology Act 2008. This came about as the result of an inquiry investigating the legislative framework provided by the 1990 Act and challenges presented by technological advance and changes in ethical and

societal attitudes. A report was published in 2005 by the House of Commons Science and Technology Select Committee Human Reproductive Technologies and the Law. In light of the report, the Department of Health undertook a review of the 1990 Act. They held a public consultation and published a white paper, Review of the Human Fertilisation and Embryology Act, within which the government presented its initial proposals to revise the legislation. Following this stage, a Joint Committee of both houses scrutinised the Government's recommendations, and provided its views on what ought to be the final form of the Bill to be brought to parliament. The Bill was brought to the House of Lords in November 2007, passing through the House of Commons through spring and autumn of 2008 and receiving Royal Assent on 13 November 2008. The main new elements of the Act pertaining to IVF are: banning sex selection for social reasons, clinics take account of 'the welfare principle' of the child when providing treatment and not the previously required 'need for a father', allowing legal recognition of both partners in same-sex relationships as legal parents when conceived through donated materials, changing restrictions on the use of data collected by the HFEA to make it easier to conduct research. Other mechanisms pertaining to IVF remain the same as in the 1990 legislation.

## 2.9.2 Policy Issues surrounding Multiple Births and Single Embryo Transfer

### Background to Public Policy: Braude Report

The HFEA regulates assisted reproduction in the UK by authority of the Human Fertilisation and Embryology Act 1990. Following a public consultation in 2007, the HFEA launched their policy of minimising the risks of multiple births from IVF treatment in January 2009. Peter Braude from King's College in London chaired the 2007 Braude report (HFEA 2007). Public meetings for both patients and clinicians were held during the consultation to allow debate and further feedback into the consultation. The group agreed that IVF children must be given a better chance to be born as healthy, full-term, singletons with a normal birth weight. The Braude report further recommended that the only safe way to reduce the risk for



IVF babies was to move towards transferring one embryo in women with the best chance of IVF success.

Experts at the London School of Hygiene and Tropical Medicine estimated that each year 126 avoidable deaths of newborn babies occur because of the increased risks of multiple births after IVF (HFEA 2007). This means that in 2003 (this is the latest year for which they have verified national figures) 126 IVF babies would not have died, if their mothers had received one, rather than two embryos during treatment, and had therefore given birth to a singleton baby (more likely to be born at full term and with a normal birth weight). The group felt that this was an unacceptable risk, given it is caused by a medical intervention. It is also avoidable; if the UK fertility sector learned from the international experience where single embryo transfer has been successfully introduced without a drop in success rates (Doyle 1996). The HFEA was set up to oversee the safety and quality of fertility services in the UK. Clinics are required by the same Act, to 'take into account the welfare of the child or children born after IVF'. The Act states: Section 13 (5): A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth. Section 2 (1) ... "treatment services" means medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children (HFE Act 1990).

The group of experts from the London School of Hygiene and Tropical Medicine argued that neither the HFEA nor clinics would be doing their job properly if they ignored the strong evidence for the much increased health risks for twins and their mothers.

The consultation took place on 23rd January 2007 in London and was convened by the Human Fertilisation and Embryology Authority. The stakeholders listed in the following table provided input and a consensus paper was drawn up.

Table One: Stakeholders in attendance at multiple births consultation convened by the HFEA, January 2007.

PROFESSIONAL ORGANISATIONS
British Fertility Society
Royal College of Obstetricians & Gynaecologists
Association of Clinical Embryologists
Royal College of Paediatrics and Child Health
Royal College of Midwives
Royal College of Nursing
British Infertility Counselling Association
Multiple Births Foundation
PATIENT ORGANISATIONS
Infertility Network UK
Twins and Multiple Births Association
Miscarriage Association
BLISS: The Premature Baby Charity
Fertility Friends
National Gamete Donation Trust
Donor Conception Network
ACeBabes
Daisy Network
Endometriosis UK
Surrogacy UK
OTHERS
National Perinatal Epidemiology Unit
National Infertility Awareness Campaign

At the consultation barriers to single embryo transfer were thoroughly discussed. Following is a summary of these barriers, extracted from the Braude consultation paper available on the HFEA website (HFEA 2007).

1) The lack and inconsistency of NHS funding for fertility treatments: This is key. If patients had their treatment funded, they would be far more ready to accept SET. The financial burden of private IVF is huge and any action taken which means more treatments are needed for a success to be reached will be resisted - particularly considering the actual risks are low and the fact that double embryo transfer (DET), will still be available to patients who seek it.

2) A desire for twin pregnancies by some patients: Unlike triplets, there's no getting away from the fact that twins are a fairly common natural phenomena. We all know people who are themselves twins or have twins. Added to this, in general twins are celebrated as special. These factors together with the lack of evidence of high risk of long term disability in twins, and the years or pain and cost that infertile patients have been through to get one child, means quite understandably, for many patients having twins, is not necessarily a negative outcome. Evidence from a German study supports this psychological desire for multiples amongst IVF patients. Despite prior information about the risk of multiple births, 81% of respondents to a survey saw no risk in twin pregnancies and a sizable minority saw no risk even in triplet pregnancies. Eighty-nine percent of the respondents rated a twin pregnancy as desirable, whereas 35% rated a triplet birth as desirable. When presented with a choice of having multiple births versus having no biological children, 99% of the respondents endorsed twins, 84% triplets and 58% quadruplets (Borkenhagen *et al.* 2007). Previously research has concluded that there are differences among patients, embryologists and clinicians in their perceptions of the desirability of multiple pregnancy. Patients rated them as highly desirable even when given information about risk (Hartshorne and Lilford 2001). This study suggests a need for a more extensive discussion/counselling to clarify risks and allow patients to talk about their attachments to the desirability of multiples and discuss in depth the complications that are associated with pregnancy, childbirth and the resulting child's lifelong health.

3) Inconsistency of freezing protocols and problems with the availability of embryo freezing: Other countries have only managed to maintain comparable success rates when including a frozen embryo transfer. For a large number of patients there are no embryos left to freeze. Added to this some clinics will only freeze blastocytes and not 2 or 3 day embryos and more frequently than not there are no blastocytes left over to freeze. In these instances patients would have to go through 2 fresh cycles and the cost, risk and heartache that that brings in order to get comparable success rates to having DET.

4) The low success rates of IVF: Whilst the success rates in some clinics are double those in others there is obviously great room for improvement. If success rates were consistently more favourable across the board SET may be more palatable. The HFEA should perhaps concentrate its efforts on finding ways to bring the poor performers up to scratch / improving success rates overall and readdress the twin rates when this has been achieved.

5) Lack of control of twin rates from other forms of fertility treatment: According to the consultation document, as many twin babies are born following ovulation induction / IUI as are born following IVF. Although this is outside the remit of the HFEA why should patients believe IVF twins pose a significant health problem that needs to be curbed when there are no moves to curtail numbers of twins from other fertility treatments? However a national study of all babies born in the UK in 2003, over a one-week period does question this argument. The study received data from 178 maternity units, of 6,913 deliveries: 6,812 (98.54%) were singleton, 100 (1.45%) twin, and 1 (0.01%) triplet. In total, 7,015 babies were born. The mode of conception and type of fertility treatment was recorded. The multiple pregnancy rate after IVF was 26% and significantly higher than after clomifene citrate and IUI therapy 7.3% (Bardis *et al.* 2005).

The consultation paper then proposed four main options to help clinics reduce multiple birth rates:

1) To increase awareness of multiple births risks among clinics and patients and to encourage the increased use of single embryo transfer.

2) To phase in a maximum twin rate of 10% which clinics must not exceed.

3) To develop HFEA guidance to define when only one embryo should be replaced.

4) To apply HFEA guidance for single embryo transfer if clinics exceed twin rate of 10%.

Summarised from ([www.hfea.braude.org.uk/239.htm](http://www.hfea.braude.org.uk/239.htm))

From these four main themes the HFEA devised its policy. It was to also contain four main elements.

1) Overall aim to reduce the UK IVF multiple birth rate to 10% in stages over a period of years

2) The HFEA will set a maximum multiple birth rate that clinics should not exceed, which will be lowered each year

3) All centres will devise their own 'multiple births minimisation strategy' setting out how they will not exceed the maximum multiple birth rate

4) The HFEA policy will form part of a wider national strategy to reduce the risk of multiple births from fertility treatment involving professional bodies, patient groups and NHS-funding bodies

Summarised from ([www.hfea.braude.org.uk/239.htm](http://www.hfea.braude.org.uk/239.htm))

## New Public Policy for every IVF clinic in the United Kingdom

The current Code of Practice for IVF clinics in the UK published by the HFEA stipulates mandatory requirements ensuring that every clinic adheres to the HFEA strategy to minimise multiple births. Each centre must have a documented strategy to minimise multiple births. This must set out: (a) how the centre aims to reduce the multiple birth rate following treatment at that centre in any calendar year, and to ensure that the rate does not exceed the maximum specified by the Authority as set out in directions and (b) the circumstances in which the clinician responsible would consider it appropriate to recommend SET to a patient (in setting out such circumstances, the centre should give proper consideration to relevant professional guidance and the criteria for transferring eggs during gamete intrafallopian transfer (GIFT). The centre must document regular audits that (a) assess progress in reducing its multiple birth rate, and (b) help evaluate the effectiveness of its strategy. The guidelines go on to state that all detailed records should be made of patients who are given more than one embryo when meeting SET criteria outlined in the centre's strategy and also when three embryos are replaced, giving reasons for such a decision. When SET is not used a patient should give written consent and be provided with information about (a) the high risk of miscarriage and complications during pregnancy (b) the higher rate of premature birth and the problems arising from low birth weight, the higher rate of still birth, and the higher rate of perinatal mortality c) the higher rate of disability and other health problems, plus the need for extended stays in hospital before and after birth, and (d) the possible practical, financial and emotional impact on the family and any children. It is apparent that regulations considering multiple births are now vigorous. They can be found in section 7 of the HFEA latest, 8th Code of Practice (HFEA 2009).

All IVF centres must have a multiple births minimisation strategy, that sets out how the centre:

- 1) intends to reduce their multiple birth rate so it does not exceed the HFEA maximum multiple birth rate for that year

2) identifies suitable cases for single embryo transfer at their clinic, using patient selection and embryo assessment criteria

Centres are required to regularly audit and evaluate the progress and effectiveness of their strategy. They must also log cases in which multiple embryos were transferred in patients who met the criteria in their strategy.

This multiple birth reduction policy was first introduced in January 2009. Targets were staged for a four year period:

YEAR ONE	24%
YEAR TWO	20%
YEAR THREE	15%
YEAR FOUR	10%

The HFEA set the Year 1 maximum multiple birth rate at 24%, the national average at the time. This meant that no more than 24% of a centre's annual live birth rate should be multiple births. It includes all births from IVF, ICSI, and GIFT treatments, using fresh or frozen embryos from either the patient's own eggs or donor eggs.

In January 2010 (year two of the multiple births minimisation policy) it was agreed that the maximum multiple birth rate across clinics should be 20%.

This investigation initially started in 2004. At that time I set out to identify issues surrounding the high multiple birth rates in UK clinics. By the completion of my thesis in 2012 this issue was being addressed by UK health policy regulation. Multiple births are now the focus of every UK clinic's annual inspection. The HFEA will support centres as they evaluate and improve the effectiveness of their multiple birth minimisation strategies. Centres that are statistically above the target will, as a first step, be asked to attend a management review meeting with HFEA staff to discuss recommended actions. This is in line with the HFEA's overarching Compliance and Enforcement Policy.

In 2012 we are now in year four of the HFEA's multiple births minimisation strategy. All UK clinics should now be required to have a multiple birth rate not exceeding 10% of live births. At the end of 2010 the HFEA evaluated the full Year 1 of the multiple births policy and the first six months of Year 2. They examined the progress of individual centres and the sector as a whole in reducing multiple pregnancies, and the impact on overall pregnancy rates. On the basis of this in December 2010, the Authority set 15% as the Year 3 maximum multiple birth rate. The Multiple Births Stakeholder Group recommended 15% as a stretching but feasible target for centres to achieve that will help maintain the good progress centres have made so far (HFEA 2010). The Year 3 maximum multiple birth rate of 15% came into effect in April 2011 and applied to all IVF births from treatments started between April 2011 and March 2012. The Authority also agreed in principle to introducing guidance around double blastocyst transfer and introducing a licence condition around the Year 3 target in October 2011. Latest data published by the HFEA suggest that clinics have trouble reaching their year 3 target of 15% and that data indicate a 19% multiple birth rate across clinics for this year. Instead of April 2012 as a proposed date to implement a 10% target, the target was delayed until October 2012. From April 2012 there will be a fee of nil to the HFEA for cycles that fulfil SET requirements.

#### Evaluation of HFEA policy to reduce multiple births

An evaluation of the first year of the new policy was undertaken by the HFEA. It concludes that the increase in SET is exclusively in women under 35 years of age and that patients who do not follow SET recommendations are having high multiple births due to improved overall success rates of IVF. This is largely concerned with the widespread use of blastocysts. It was found that embryo quality is more important than age in predicting success and effective grading is very important for SET to work well. Effective freezing protocols are also vital to ensure surplus embryos survive (HFEA 2010).

The charts in appendices 2 and 3 indicate a need to target elective single embryo



transfer at IVF patients over the age of 35 as well as for patients under this age. Appendix 2 indicates that very few patients over 35 are opting for single embryo transfer. Appendix 3 indicates what appears to be a decrease in multiple births for the age group 35-37 years and an increase in multiple births for patients aged 38-39. Although there are significant fluctuations over the period the data appear to indicate an overall increase in the multiple pregnancy rate for patients aged 35-39 years of age. This would seem to negate the decrease in multiple pregnancy rates in those IVF patients under 35 years of age. The increase in multiple rates in those patients over 35 is likely due to the effectiveness of blastocyst transfer. The evaluation reported that patients were influenced in their decision to take up SET or opt for DET instead because of several factors:

- 1) Funding arrangements- if patients were dependent on NHS funding it was necessary for funding arrangements to be supportive of the technique in that any necessary frozen cycle treatments were included in the IVF treatment or offered at a reduced price.
- 2) If information in detail was given about the advantages of SET was given to them by staff at the outset of their treatment. Clear information is needed and should to be given consistently by all staff. Face-to-face information was considered important. Patients thought that leaflets and websites were less likely to influence treatment decisions. Some patients said that they were given information regarding elective single embryo transfer on the day of their embryo transfer. This was found to be unconvincing and confusing.
- 3) Patients reported that they desired a forum within the clinical setting to discuss SET. This could be either in a support group or counselling session.

From the evaluation it is apparent that counselling and other support meetings associated with the clinic could be a forum to discuss and promote SET. The 2009 policy evaluation undertaken in 2010 suggested that the majority of patients who did not choose SET did so because they thought that not choosing it could improve their pregnancy chances. Also, a large number thought that the risks of multiple

births were acceptable. Clear information and discussion is needed on a face-to-face level with patients about the high success rates of SET and the health risks to the baby and parent that occur from multiple embryo transfer. This could be done through counselling and through liaison with neo-natal units in the UK. Data can be obtained from such units to emphasise the potential dangers for those babies that are placed there as a result of low birth weight and other health risks connected to a multiple gestation. These units can provide factual evidence to back the information given by IVF clinic staff about potential health risks.

A second evaluation of SET policy for 2010 was undertaken by the HFEA in 2011. Findings were almost identical to the previous year and there was an indication that the situation regarding multiple births remained stagnant. A patient survey showed that about one in ten patients said that the information they received about SET from different staff members was inconsistent and one in twenty were not given any information about the risks of multiple births. When the Multiple Births Stakeholder Group discussed the findings of this latest multiple birth data it concluded that the same difficulties still exist a year later. IVF clinics in the UK were still not uniformly informing patients about SET options. There was still an inconsistency of information given from different members of staff in clinics. Patients also still see twins as a desirable outcome. They felt that there's not enough awareness of the psychosocial difficulties of twins and work should be done to engage more with neonatal units so patients are more aware of the costs and risks of babies being in neonatal units (HFEA 2012).

In January 2012, the HFEA commissioned a patient a further SET evaluation survey. This was now three years after the introduction of clinic wide SET policy. This survey showed that about one in 10 patients said the information they received about SET from different staff members was inconsistent and one in 20 were not given any information about the risks of multiple births. When the Multiple Births Stakeholder Group discussed the findings of this latest multiple birth data it concluded that the same difficulties still exist with informing patients: that there was still an inconsistency in information given from different members of staff coupled with the fact that some patients still see twins as a desirable outcome. One study

specifically focused on the provision of risk information about twins and found that women's initial preference for DET was related to beliefs that the chance of pregnancy was higher with DET vs. SET. Providing risk information increased the desirability of elective single-embryo transfer and decreased the desirability of twin pregnancy among both men and women. The study found that cautious patients, preferring transfer of fewer embryos, balance desires to maximise the chance of pregnancy with acceptance of risks associated with twins. Less-cautious patients may be motivated by beliefs about the influence of age, desires for, and likelihood of twin pregnancy. Information about risks may affect these groups differently and diverse patient motivations may require tailored information to promote the adoption of SET (Newton *et al.* 2007) This psychological mindset is the more difficult hurdle for policymakers to overcome and one where the role of a counsellor for clarification and discussion could be invaluable. The HFEA stakeholder group felt that there is not enough awareness of the psychosocial difficulties of twins and work should be done to engage more with neonatal units so patients are more aware of the costs and risks of babies being in neonatal units (HFEA 2012).

All of the public feedback to the HFEA evaluating SET policy the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> year after its introduction lends support for the proposal that counselling within the clinical setting may be an appropriate forum for parents to gain information about and discuss their concerns regarding SET. This is confirmed by another study in 2003. In this study the way that information about SET was given to patients was assessed. Patients' were slightly more likely to find SET acceptable when information was delivered face-to-face (in this study this was done by clinic staff not counsellors) rather than being given only written information (Murray *et al.* 2003). The feedback from patients to the HFEA suggests that information regarding SET in the UK clinics is inconsistent and confusing. This hinders any clinic's progress in meeting their targets in compliance with policy to decrease multiple births. The counsellor is in a unique position to impart information about SET as they are trained in communication and are qualified to identify and discuss the concerns of each individual patient. They may be able to fully inform the patient of all issues pertaining to SET before any decision is made to embark on such treatment and later be able to advise and counsel if any further issues or

questions arise at any time during the clinical treatment process.

### 2.9.3 Research Surrounding Single Embryo Transfer

In terms of success rates, the latest research from the University of Aberdeen demonstrates that elective single embryo transfer (eSET) results in a higher chance of delivering a term singleton live birth compared with double embryo transfer. Although this strategy yields a lower pregnancy rate than a double embryo transfer in a fresh IVF cycle, this difference is almost completely overcome by an additional frozen single embryo transfer cycle. The multiple pregnancy rate after eSET is comparable with that observed in spontaneous pregnancies (McLernon 2010:341). This study is important because it could be used to frame the way that information about single embryo transfer is given. Instead of one cycle of double embryo transfer a 'package' of single embryo transfer followed by a single frozen one carries the same rate of pregnancy success but none of the health risks associated with multiple gestation. This needs to be fully explained to each and every patient through face-to-face discussion before treatment starts. Counsellors attached to clinics could be qualified and appropriate to do this.

A recent study published in the *Lancet* suggests that SET should however, NOT be the first choice for IVF patients over 40 years of age. Researchers at the Medical Research Council in Bristol, led by Professor Debbie Lawlor, quantified the risks and benefits associated with single versus multiple embryo implantations in women younger and older than 40 years. 33,000 live births were analysed from 124,000 IVF cycles from across the UK. Their findings provide some support for the transfer of two embryos in women older than 40 years, because the risks of pre-term and low birth weight were lower than those in younger women. Generally women in this age group have lower chances of falling pregnant, and so were less likely to have a twin pregnancy after the implantation of two embryos (Lawlor & Nelson 2012).

With regard to health issues surrounding multiple gestations, recent research in

Sweden demonstrates that SET has important, positive effects on health outcomes for IVF children and their mothers. Swedish researchers have demonstrated that Sweden's dramatic increase in SET over the last 5 years, to 70% SET, has resulted not only in the expected decrease of multiple births and associated pre-maturity, but also in measurable, better health outcomes for IVF children and their mothers. For mothers, the increased risk of pre-eclampsia (dangerously high blood pressure) and PROM (premature rupture of membranes) during pregnancy, previously demonstrated after IVF, has now virtually disappeared. For children, the risk of neonatal death was reduced from three times the background risk to nearly nil. Neonatal diagnoses like cerebral bleeding, respiratory problems and sepsis also decreased significantly, as did the risk of cerebral palsy. During the same time period, efficacy of IVF did not suffer, with success rates remaining just below 30% of deliveries per embryo transfer with only 5% being twins. The researchers conclude that a high proportion of SET leads to fewer multiple births and thereby to less pre-maturity and low birth-weights. This consequently leads to a number of better health outcomes for mother and child (B Kallen *et al.* 2010).

This chapter has provided an introduction covering various essential aspects of IVF. The purpose of the information contained in this chapter is to help the reader understand a few of the issues involved in IVF and multiple births and give them a basic understanding for future chapters.

## CHAPTER THREE

### BACKGROUND: INTERNATIONAL PERSPECTIVES

**This chapter aims to situate IVF in the UK within an international context. In doing this I hoped to gain some insight into the effectiveness of current legislation and public health policy concerning multiple births in a comparative fashion. Policy decisions made in one country inevitably inform policy debates in other countries. Examining IVF internationally is one route to understanding the global landscape and the intertwining of cultures through the IVF technology. Initially I look at IVF on a global scale. Then I focus on Europe and conduct an analysis from some of the available data in there. Lastly I focus on North America. After examination of some information available from the United States, I turn to Canada. I lived there when I started my research and was an IVF patient and an attendee at some support groups. No central data collection exists for IVF pregnancies so my analysis there was qualitative with an emphasis upon observations.**

#### **3.1 IVF in an International Context**

In 2010, The International federation of Fertility Societies Surveillance project recorded data from 162 countries (Jones *et al.* 2010). On the topic of multiple births the report acknowledged that the education of patients and the community are important, although some patients prefer twins, in spite of full knowledge of the risks of multiple pregnancy. Methods that have been used to reduce the likelihood of multiple pregnancy have been single embryo transfer (SET) and increasing time in culture for the embryos to reach the blastocyst stage for transfer. Reviewing the data from 1996 to 2003, it was considered that the voluntary guidelines had had an effect, but embryo selection techniques needed to improve and socio-economic issues that pressurised patients and physicians to transfer more embryos needed to be addressed.

In the report, SART data for the US in 2006 were reviewed (Sundaram *et al.* 2009)

and 48% were multiple deliveries, compared with 51% for the 2003 data. Those who were at highest risk were those who underwent transfer using fresh embryos, either their own (31%) or donor eggs (39%). ART contributed 1% of all births in 2006, but accounted for 18% of multiple births. The point is made that “to minimise the adverse maternal and child health effects associated with multiple pregnancies, ongoing efforts to limit the number of embryos transferred in each ART procedure should be continued and strengthened.” In Canada, where all 25 clinics reported their data for 2006 per cycle started (Gunby *et al.* 2006), one or two embryos were transferred in 67% of cycles and the multiple birth rate was 30.3% showing only a slight decrease over previous years. For a woman’s own oocytes the live birth rate was 27.1% and the multiple birth rate was 30.3%. For donor oocytes the live birth rate was 33.6% and the multiple birth rate was 37.3%; for frozen-thawed embryos the live birth rate was 24.3% and the live birth rate was 22.5%.

The report went on to detail continuing calls for elective SET (Gerris 2009). A review of the annual reports from all IVF units in Sweden to the National Board of Health and Welfare from 1991-2004 showed that despite a successive reduction in the number of embryos transferred to SET, delivery rates were maintained at around 26%. During that time the multiple birth rate decreased dramatically from about 35% to around 5% (Karlstrom and Bergh 2007). Although it is agreed that SET minimises twin pregnancies it has also been claimed that it results in lower live birth rates (Baruffi *et al.* 2009).

The report cited a population based study in Australia and New Zealand from 2002-6 (Wang *et al.* 2010) which examined patients’own gamete embryos used to deliver a “healthy baby”, described as “a single baby born live at term, weighing  $\geq 2500\text{g}$  surviving for at least 28 days post-birth and not having congenital anomalies”. The numbers of transferred embryos were grouped as single embryo, double embryo and three or more embryos. The live delivery rate was significantly higher for transfer of fresh blastocysts (27.9%) than for blastocysts cultured from thawed cleavage embryos (22.0%), fresh cleavage embryos (21.7%), thawed blastocysts (16.3%) and thawed cleavage embryos (15.2%). Natural selection occurs during the additional two or three days in culture and there are fewer

transfers of blastocysts than cleavage stage embryos. Nevertheless it was reported that the proportion of blastocyst transfer has increased from 13.4% in 2003 to 30.6% in 2007 and SET from 32% to 64% in that time. It was suggested that an optimum practice model to maximise the birth of a healthy baby is the transfer of blastocysts and the freezing of cleavage embryos in fresh cycles and subsequent transfer of blastocysts cultured from these thawed cleavage embryos. Vitrification should also have an impact and data from this newer freezing technique are awaited. Where there are adequate numbers of good quality cleavage embryos, a proportion should be frozen at the cleavage stage and three or four cultured on to the blastocyst stage with a single blastocyst being transferred. This could be applied in younger patients in their first ART cycle, where the loss on the further culture is likely to be minimal.

Details about embryo transfer practices extracted from the information correlated from the 162 countries surveyed can be seen in appendix 7. It was reported that there were 20 countries that provided details of the limits that are prescribed by statute. Of these, Sweden has been exemplary in voluntarily moving to predominantly SET and Belgium reinforces this by using it to influence reimbursement. Italy's law specifying that all the embryos produced after a maximum of 3 oocytes have been fertilised must be transferred, except when there are maternal risks, has been challenged successfully in the courts. For other countries there are different age related restrictions and the maximum number varies. There are no penalties for violations in some countries, but they are severe in Germany.

There are 23 countries that are subject to guidelines relating to IVF transfer numbers. Two countries have published theirs, the USA (ASRM 2009) and Canada (SOGC 2008). In both Australia and the UK clinics have been exhorted to introduce a strategy to minimise the multiple pregnancy rate.

Similarly, 11 countries indicated that there are neither statutes nor guidelines regulating their practice. However 36 countries responded and indicated that there was a maximum that was customarily transferred. This ranged from 2 countries,



Namibia and Swaziland, which had a limit of 2, 14 had an upper limit of 3, 12 had one of 4, while 6 had an upper range of 5, Bosnia, Cameroon, Ethiopia, Libya and Nigeria. Kuwait had a limit of 6 and in Panama there was no limit.

The report indicated that there seemed to have been slow progress in reducing the number of embryos transferred at IVF since the last survey in 2007, for this survey data were gathered from only 59 countries. The numbers are high in those countries in which ART is less well developed, reflecting the earlier years of the now more experienced countries and perhaps a difference in embryological laboratory methodology. Competition between clinics and the drive for “success” are potent obstructions to change, but education of clinic staff and the public should be much better. State support needs to be markedly extended, although the socio-economic argument has to be better put. In more experienced environments recourse to blastocyst transfer should be encouraged and vitrification may allow a better outcome after transfer of fewer embryos (Jones *et al.* 2010).

### **3.2 IVF in Europe in an International Context**

**The following data were extracted and adapted from ESHRE’s website and aim to give a synopsis of IVF in the context of ART practice in Europe (ESRE 2013).**

ESHRE was founded in 1985 to facilitate study and research in the field of reproductive medicine and science. The society is self-funded through membership fees and is non-profit making. It operates from Belgium and co-operates with other scientific and medical societies, universities and other organisations with related interests. Its research findings are published in *Human Reproduction*.

Europe leads the world in ART, initiating approximately 55% of all reported ART cycles. In 2010, the latest year for which figures are available, 565,031 treatment cycles were reported from 31 European countries. This compares globally (in 2010) with 147,260 cycles from the US and 61,774 cycles from Australia and New

Zealand. The number of cycles performed in many developed countries has grown by 5-10% per annum over the last few years, but that growth is now showing signs of slowing. In 2010 France (79,427 cycles), Germany (74,672), Italy (58,860), Spain (58,735) and the UK (57,856) were Europe's most active countries. In the Nordic countries, Sweden leads the table with 17,442 cycles, followed by Denmark (15,863). The most active countries in the world are Japan and the USA.

The Nordic countries and Belgium have the highest ART availability in terms of cycles per million population. In Belgium, Denmark, Finland, Iceland, Norway, Slovenia and Sweden more than 3.0% of all babies born were conceived by ART. By contrast the proportion in the USA - with 57,569 ART babies born - was estimated to be slightly more than 1% of total births. Around 1.5 million ART cycles are performed each year worldwide, with an estimated 350,000 babies born. An analysis of world data for 2007 put average delivery rate from ART treatment at 21.7% per aspiration and 27% cumulative from a single started treatment cycle. Large differences exist between countries in the number of embryos transferred and resulting multiple births. However, there is a consistent trend towards transfer of fewer embryos. The overall average number is 1.75 embryos per transfer.

In Europe the multiple delivery rate per embryo transfer has declined steadily since 2000 from 26.9% to 19.2% in 2010 compared to a multiple delivery rate of 33% in the US (29% twin, 2.5% triplet or more deliveries). Sweden has the lowest multiple delivery rate in the world. In 73.3% of all cases a single embryo was transferred. In Europe in 2010 the mean pregnancy rate per embryo transfer was 35.5% after IVF, 32.1 % after ICSI, 23.8% after frozen embryo transfer and 45.8% after egg donation. Rates are higher in younger (<35 years) patients.

The most common fertilisation (treatment) technique is ICSI. Overall, ICSI accounts for around two-thirds of all treatments worldwide, and conventional IVF around one-third. However, these proportions vary greatly between countries, even though outcome rates with each technique are comparable. Success rates from frozen embryo transfer are increasing, as are the number of frozen embryo transfer cycles. Vitrification, as an efficient cryopreservation technique, has improved the

outcome of both embryo and oocyte freezing. Ovarian hyperstimulation syndrome is a complication related to ART. In 2010 there were 1484 OHSS cases recorded in 25 out of 31 European countries reporting to ESHRE, making up 0.3% of cycles. Russia (401), Spain (180) and Italy (162) reported the highest number of patients with OHSS.

Summarised from ART Factsheet (ESRE 2013).

### 3.2.1 IVF and European Public Health Policy

Currently the only framework of law and regulation to govern IVF in Europe is 'The EU Tissues and Cells Directive 2006'. This sets out standards of safety and quality for the handling of gametes and embryos. This extends to standards involved in their creation. Currently couples are screened for diseases like HIV (human immunodeficiency virus) and hepatitis before their first treatment cycle and, once completed, are considered virus-free for the remainder of the course of their treatment. (EUTCD; EC/2004/23). Clinics are also now also regulated by European Care and Quality Standards and need to be ISO 9000 standard.

The EU government funded a project in the 1980s, which considered grounds for a comprehensive public policy to oversee IVF procedures in the EU (Glover 1999). This report was very useful to clarify the issues and concepts that are involved in formulation of a far-reaching legislative framework. The report is a useful insight into this project because it focuses upon the institution of the family. This investigation attempts to analyse IVF from a sociological perspective and it is important to realise that new reproductive methods not only modify the institution of the family but their development is itself influenced by the role of family within society. A historical sketch of the family is provided, spanning over 5 decades. The discussion states that although it is felt that new forms of reproduction may change the family, their developments itself is likely to have been caused in part by changed, more flexible, attitudes towards the family. Social decisions influence which knowledge grows and which technology is developed. It is apparent that

social changes have demanded this technology rather than technology being purely scientifically led. The spread of contraception has enabled people to regard having children as a matter of choice, and also to think more readily of sex as independent from procreation. Consequently, it seems natural to extend choice about children to the infertile and accept procreation as independent of sex. As reproductive techniques become more common they will also shape peoples outlook about what it means to be a parent.

The report later considers the development of law or regulation to govern IVF in Europe. The Working Party of the Glover Report, advocates a European regulatory body to control reproductive technologies. It is strongly felt that non-specialist members of the public should have a voice in this. To facilitate such involvement, it was felt that the level of public information and debate has to be raised. Community awareness is often minimal because scientific information rarely goes directly to the public; rather, it is taken up selectively, on grounds of news value by the media. It was thought that mechanisms should be created by which new research and its application can be guided by the wider values of society. Scientists should also adopt willingness to engage uncondescendingly in public debate and warn about likely problems. The recommendation is that public debate can be facilitated throughout the increased use of public hearings with an official committee, followed by Parliamentary debate with a view to legislation where appropriate. The report considers informed public debate to be crucial for a widespread discriminating evaluation (Glover 1999).

Currently in 2011, background research for this chapter demonstrates disparities between European countries on diverse aspects of fertility regulation - including the cost and success rate of fertility treatment, the availability and anonymity of sperm and egg donors, the amount that donors are allowed to be paid, the maximum number of embryos that can be implanted in a woman's womb, and whether and when embryos are allowed to be genetically screened. Reproductive tourism tends to be criticised from one of two perspectives - either as an indictment of overregulation in the tourist's home country, so that women are forced to travel unnecessarily in order to receive treatment; or as an indictment of under regulation

in the tourist's destination country, so that women are tempted to undergo procedures that are overly risky and should be restricted (Robertson 2004). The disparity of European fertility regulation is underpinned by a disparity of cultural attitudes towards fertility issues, and these underlying cultural differences can be difficult to negotiate. Regulations often emphasise social policy priorities such as how the family should be constituted (Herz 1989). This emphasis on family creation in certain European countries and the way in which it influences policy pertaining to IVF, illustrates how a nation's moral economy will shape its priorities.

### 3.2.2 IVF across Europe

Data gained from ESHRE's registers helps to further clarify the global situation with regard to multiple births in IVF clinics. This situates the United Kingdom within the European context. From this data it is apparent that, despite the 2008 introduction by the HFEA of complex apparatus governing public health policy concerning the reduction of multiple births and the promotion of SET it is clear that the UK is not a forerunner in the European context in terms of promoting safer IVF practices. The data collected in this chapter demonstrates that other countries, namely, Sweden, Belgium, Finland and Norway have been practicing much higher levels of SET than the UK over the last two decades. At the time of the start of my research (2004), in Europe, the UK was the only country that statutorily required clinics to publish data about their activities. Since 1997, ART data in Europe have been collected and reported in 12 manuscripts, published in *Human Reproduction*.

The latest report (Ferraretti *et al.* 2013) displays data collected in 2009. Data is collected by the EIM Consortium for the European Society of Human Reproduction and Embryology (ESHRE); cycles started between 1st January and 31st December have been collected on a yearly basis; the data are collected by the National Registers, when existing, or on a voluntary basis.

The 13th European in vitro fertilization (IVF)-monitoring (EIM) report presents the

results of treatments involving assisted reproductive technology (ART) initiated in Europe during 2009. The report seeks to acknowledge any changes in the trends compared with previous years. It found that despite some fluctuations in the number of countries reporting data, the overall number of ART cycles has continued to increase year by year and, while pregnancy rates in 2009 remained similar to those reported in 2008, the number of transfers with multiple embryos (3+) and the multiple delivery rates declined.

Data were collected from 34 countries (-2 compared with 2008), 1005 clinics reported treatment cycles of IVF numbering 135 621, intracytoplasmic sperm injection ICSI, numbering 266 084, frozen embryo replacement (FER, 104 153), egg donation (ED, 21 604), in vitro maturation (IVM, 1334), preimplantation genetic diagnosis/screening (PGD/PGS, 4389) and frozen oocyte replacements (FOR, 4278). European data on intrauterine insemination using husband/partner's semen (IUI-H) and donor (IUI-D) semen were reported from 21 and 18 countries, respectively. A total of 162 843 IUI-H (+12.7%) and 29 235 IUI-D (+17.3%) cycles were included. Data available from each country are presented in tables.

In 21 countries where all clinics reported to the ART register, a total of 399 020 ART cycles were performed in a population of 373.8 million, corresponding to 1067 cycles per million inhabitants. For IVF, the clinical pregnancy rates per aspiration and per transfer were 28.9 and 32.9%, respectively and for ICSI, the corresponding rates were 28.7 and 32.0%. In FER cycles, the pregnancy rate per thawing was 20.9%; in ED cycles, the pregnancy rate per transfer was 42.3%. The delivery rate after IUI-H was 8.3 and 13.4% after IUI-D. In IVF and ICSI cycles, 1, 2, 3 and 4+ embryos were transferred in 24.2, 57.7, 16.9 and 1.2%, respectively. The proportions of singleton, twin and triplet deliveries after IVF and ICSI (combined) were 79.8, 19.4 and 0.8%, respectively, resulting in a total multiple delivery rate of 20.2%, compared with 21.7% in 2008, 22.3% in 2007, 20.8% in 2006 and 21.8% in 2005. In FER cycles, the multiple delivery rate was 13.0% (12.7% twins and 0.3% triplets). Twin and triplet delivery rates associated with IUI cycles were 10.4/0.7% and 10.3/0.5%, following treatment with husband and donor semen, respectively.

The 13th ESHRE report on ART shows a continuing expansion of the number of treatment cycles in Europe, with more than half a million of cycles reported in 2009. The use of ICSI has reached a plateau. Pregnancy and delivery rates after IVF and ICSI remained relatively stable compared with 2008 and 2007. The number of multiple embryo transfers (3+ embryos) and the multiple delivery rate have shown a clear decline. The method of reporting varies among countries, and registers from a number of countries have been unable to provide some of the relevant data such as initiated cycles and deliveries therefore results should be interpreted with caution (Ferraretti *et al.* 2013).

### 3.2.3 Number of embryos transferred and multiple births in Europe

The number of embryos transferred during any one IVF cycle was the most important data recorded in the reports as it is directly correlated with the multiple birth rate. The data extracted from the ESRE reports showed the average number of embryos transferred during any one IVF cycle in 1999, 2005 and 2009. In November 2001 the ESHRE report which detailed activity from IVF treatments initiated between January and December 31, 1999 in 18 countries. In 1999, 14 of the 18 reporting countries provided embryo transfer information (Appendix 8). This report provided the best available information about IVF practice in Europe during the initial start of my research and details the number of embryos transferred during IVF, on a country-by-country basis. This data however is incomplete because reporting and collection of information was not compulsory during the time of my initial study. At the time of my initial study there was discussion of progress being made in the regard. ESHRE also noted difficulties gathering uniform data because of different definitions used in each country. Some countries, for example, may define a delivery only when a child is born alive, while other countries may include all deliveries in their data. The report also mentions the problem of the lack of follow-up of deliveries; data may be collected about an IVF cycle but this information is not complete unless details are also further recorded at the time of birth 40 weeks later (Anderson and Nygren 2001). For 2005 data, I examined 27

of 30 reporting countries for embryo transfer practices (Appendix 9). These countries all gave data for the report although I omitted Belgium and the Netherlands, as they did not give information about embryo transfer (Anderson *et al.* 2001). For 2009 data I gained information from 32 of 34 countries for embryo transfer data (Appendix 10). I excluded Croatia and Cyprus who gave no information pertaining to embryo numbers transferred (Ferraretti *et al.* 2013).

In 1999, the proportion of IVF cycles transferring only one embryo remains relatively constant with a mean of approximately 11% for reporting countries. Finland had the highest proportion of single embryo transfers with 16.4%; the lowest was Hungary with 7.5%. The UK conducted 9.2% of IVF cycles as SET cycles. In 2005, data was available from far more countries and results were very variable. The mean showed as 20% of cycles, considerably higher than 1999. Sweden conducted 69.4% of its cycles as SET cycles and Belgium, Finland and Norway also showed high numbers. Bulgaria conducted the lowest percent of SET at 8.5%. Other countries showing low rates were Lithuania, Ireland and the UK. The UK conducted 9.9% SET cycles. This had not greatly increased from 1999 figures. In 2009, the mean number of single embryo transfers across countries showed as being 24.2% of all cycles. Sweden conducted the highest number of SET transfers at 70.7%. Other countries demonstrating high SET practices were Finland, Norway and Belgium. Moldova conducted the lowest percent SET at 8.7%. Other countries showing low rates were Bulgaria and Lithuania. The UK conducted 22.7% SET cycles. This is substantially higher than in 2005.

The proportion of dual embryo transfer varies in 1999. The mean number of cycles transferring 2 embryos was 37.4% across clinics. Sweden has the highest proportion with 85.1%, whereas in Russia only 14.1% of IVF transfers used two embryos. In the UK 47% of IVF cycles transferred 2 embryos. In 2005 data shows slightly less variability and the mean is higher at 56.1%. IVF transfers involving 2 embryos represent the majority type of transfer in 2005. Croatia has the highest proportion at 86.6%; closely followed by the UK with 85.3% Greece was the lowest with 21.9%. Bulgaria and Serbia also showed lower scale percentages. For 2009 data, the mean percentage of dual embryo transfers across countries was 57.7%. This has not changed dramatically since 2005 and dual embryo transfer still represents the majority type of transfer. The Czech Republic shows the highest



proportion of these transfers at 72.8%, closely followed by the UK, with 72.1% of this type of transfers. Lithuania showed the lowest percentage of this type of IVF transfer at 13.2% of all transfers.

In 1999, all the reporting clinics transferred 3 embryos. The data indicated wide differences between reporting countries. The range of transfers in clinics using 3 embryos varies between approximately 4% and 59% across countries. Two countries reported very low rates of triple embryo transfers. In Sweden and Finland three embryos were used in 4.4% and 9.4% of transfers respectively. Germany showed highest figures at 59%, this was followed by Hungary at 50%. Over half the reporting countries transferred 3 embryos in over 40% of their IVF cycles. Figures for the UK were 43.7%. By 2005 these figures were less variable. Sweden, Denmark and Norway no longer transfer 3 embryos. Italy showed the highest figures a 50.4%. The UK has now dramatically dropped the practice with figures of 4.8%. In 2009 data also showed variability. The percentage of occurrence of this type of transfer was 16.9% across countries. Finland, Iceland, Norway and Sweden did not practice these transfers. Macedonia, Moldavia and Montenegro all showed a strong support for triple embryo transfer and numbers in Italy were still high. In the UK triple embryo transfer accounted for 5.3% of all transfers. The variability demonstrated by countries across Europe indicate that many social, political, religious and cultural factors influence family formation and the fertility practices implemented in creating these families.

Many countries were, and are, transferring four or more embryos. Across all of the reporting clinics in 1999, more than 4 embryos were transferred in 17% of all IVF transfers. There are fairly wide differences between countries: the range of transfer of more than 4 embryos was between 0% and approximately 55% during any IVF cycle. Countries transferring the most embryos were: Russia 54.7% and the Czech Republic 33.3%. In Southern Europe: Greece 37.5%, Spain 31.9% and Portugal 25.8%. Hungary transferred 24%. Both of the Eastern European countries that reported data were transferring a high proportion of more than four embryos during IVF treatments. By 2005 more than 4 embryos were only being transferred in 2.3% of cycles across Europe. Thirteen countries reported this

practice. Bulgaria transferred more than 4 in 34.8% of IVF cycles. Serbia and the Ukraine also showed high numbers. All countries reporting this practice were situated in Eastern Europe with the exception of Greece. In 2009 more than 4 embryos were only being replaced in 1.2% of cycles across Europe. Clinics in Lithuania and Serbia account for a lot of this practice.

In 1999, the mean multiple birth rate across 16 reporting countries is 28.9% (Anderson and Nygren 2001). Countries showing the highest rates were in Eastern and Southern Europe. Nordic countries showed the lowest rates. In comparison the mean multiple birth rate for the US in 1999 was 36.5%. This figure is analogous to the figures in Eastern and Southern Europe. The HFEA reported the multiple birth rate for the UK in a slightly different reporting period (1st April-31 March 1999) to be 29.3%. This is higher than the average rate across Europe. By 2005, the mean multiple birth rate across 14 reporting countries was 20% (Anderson *et al.* 2009). Highest figures were reported from Albania at 28.6%. Lower figures again came from Nordic countries with Finland reporting 11.7%. The UK shows a rate at much higher than average during that time period at 26%. The US shows at rate of 37.3% in 2005. In 2009 the HFEA introduced policy to stage SET into clinics and ultimately decrease the IVF multiple birth rate to 10%. In 2009 the mean multiple birth rate across countries is 20.2% (Ferraretti *et al.* 2013). The highest figures are reported from Lithuania and the lowest from Sweden. Figures from the UK demonstrate 22.8% multiple birth transfers for non frozen IVF transfer deliveries.

Overall, this analysis identifies a need for UK clinics to lower their high multiple birth rates. The multiple birth rate in the UK dropped slightly from 1999-2009 but not in line with decreases shown in other European countries. Data gathered for this analysis demonstrates that the UK has some of the highest multiple birth rates in its clinics in the whole of Europe. In 2009 the practice of dual embryo transfer was the second highest in Europe. This indicates a need for the instatement of practices in IVF clinics in the UK to encourage SET. Public policy introduced in 2008 by the HFEA and currently in its final stages addresses this. However, it is interesting to note that not all European countries with successful SET programs in

their IVF clinics have promoted them via legislation. Scandinavian countries have successfully promoted SET in their IVF clinics via successful professional and public education programs without the presence of restrictive legislation. This is sociologically interesting as it demonstrates that political and social culture has been able to shape medical procedure in the absence of legal doctrine. This in turn may influence the culture of the clinic in terms of patient opinion as policy and the legislation behind it may be seen as oppressive and detracting from patient autonomy.

### **3.3 Reproductive Medicine in the United States**

There is no formal legislative framework in the United States governing Reproductive technologies. However the American Society for Reproductive Medicine (ASRM) provides a benchmark for procedural standards. The subgroup of the ASRM, The Society for Assisted Reproductive Technologies (SART) has developed a reporting process that lends legitimacy to clinics that participate in data collection mechanisms. Individual IVF clinics, clinicians and bioethicists have called for the regulation of IVF technology, including more guidelines, laws, and technology assessment. Some especially favour impetus from professional associations, with participation from the public (Figge 1998).

The ASRM was founded in 1944 and is a non-profit making, nationally and internationally recognised leader for multidisciplinary information, education, advocacy and standards in the field of reproductive medicine. Since 1950, the ASRM has published *Fertility and Sterility*, a leading peer-reviewed medical journal in obstetrics and gynaecology. Additionally, the Society produces two newsletters, *ASRM News*, and *Menopausal Medicine*. The Society's Ethics Committee publishes ethical concerns regularly. To provide assistance about diagnostic and therapeutic dilemmas, the ASRM Practice Committee also produces timely reports in the form of guidelines, minimum standards, committee opinions, and technical and educational bulletins. Also published are the ASRM Patient Education Committee's Patient Information Series booklets and Patient Fact Sheets, which are designed to help the patient understand the complexities of reproductive

disorders and their treatment (ASRM 2013). In 2009, The American Society for Assisted Reproductive Technology and American Society for Reproductive Medicine published guidelines indicating that any patient should receive only one or two embryos during any IVF transfer (ASRM 2009).

The American Society for Reproductive Medicine (ASRM) and the European Society of Human Reproduction and Embryology (ESHRE) are the two largest societies in the world whose members comprise the major experts and professionals working in the field of reproductive medicine and embryology. These societies had their first 3-day joint scientific meeting in March of 2012. The goal was to present and debate key topics, as well as modes of practice in reproductive medicine and to discuss recent developments in the field. Although different opinions and approaches sometimes exist on the two sides of the Atlantic, an appreciation and acceptance of these differences was evident, and there was more commonality than divergence of opinion (Gianaroli *et al.* 2012).

In this meeting, single embryo transfer was described as a 'hot topic' and points raised are summarised in brief here. There was a general consensus that elective Single Blastocyst Transfer (eSBT) should be indicated in young, good-prognosis patients with good quality embryos thus promoting a reduced twin rate without decreasing the chances of pregnancy. In addition, the high survival rate of cryopreserved blastocysts was considered to greatly contribute to good cumulative pregnancy rates (Mesut *et al.* 2011).

The maternal and neonatal risks of multiple gestations and deliveries associated with their socioeconomic costs, promoted the adoption of advocating elective single-embryo transfer (eSET) by some countries, particularly in Northern Europe. After almost a decade of this experience, the generalized use of eSET in a fresh cycle combined with the subsequent transfer of a frozen embryo provides outcomes that are similar to one fresh cycle with dual embryo transfer (DET). The main difference resides in the incidence of multiple live birth rates that drops significantly from 22–29% after DET to 1% in eSET (McLernon *et al.* 2010).

The measure of treatment success is crucial to the acceptance of eSET, for which the focus needs to be shifted away from the results of a single fresh cycle to results of cumulative cycles. In this case, eSET matches or outperforms DET (Practice Committee of Society for Assisted Reproductive Technology; and Practice Committee of American Society for Reproductive Medicine, 2012). As a prerequisite to this strategy, the cryopreservation program must be efficient and reliable. Patients' characteristics should be carefully evaluated when deciding on the transfer policy, since poor prognosis factors such as advanced female age, poor embryo quality and some infertility factors may dictate the need for DET (Lawlor and Nelson, 2012).

The situation is somewhat different in the US. Live birth rates in the US are higher than in those countries with a greater percentage of eSET cycles. These differences cannot be explained by the larger number of embryos transferred (Gleicher et al., 2007). However because of the expectation of couples in the US for higher pregnancy rates and the fact that most cycles have to be paid for by the couple, there has been some reluctance in adopting a strict eSET program. Nevertheless there is keen awareness that eSET should be seriously considered in good prognosis patients with good embryo quality (Practice Committee of Society for Assisted Reproductive Technology; and Practice Committee of American Society for Reproductive Medicine, 2012). Not to be forgotten is patient autonomy, and the couples' choice. A survey a few years ago reported that many couples strongly favour twin pregnancies (Practice Committee of American Society for Reproductive Medicine, 2012). However, proper education and information given to patients significantly changed this position (Newton et al. 2007).

### **3.4 IVF in Canada**

Canada is included in this investigation for two reasons. Firstly, as an IVF patient in Toronto, Canada I had the privilege of experiencing first hand IVF procedures in a clinic setting. My experiences largely contributed to the motivation behind the formation of my subsequent research. As a patient, I was able to talk with other

patients both in a clinic and support group setting and speak to doctors in both a clinic and wider hospital setting. These experiences form a valuable contribution to my overall investigation and are summarised over the remainder of this chapter. Secondly, studying IVF practices in Canada situates the UK within a global context. Interesting, unlike the US, Canada has devoted much time and money to the formation of public policy to govern reproductive technologies. Unlike the UK this public policy has faced barriers to its provision because of provincial/federal differences in the law and because of parliamentary delays. This positions Canada between the total non-regulation of the US and the apparatus of regulation it seeks which in many ways is modelled upon UK regulation.

### Public Health Policy and Self-Regulation

At the initial start of my research Canada was an anomaly because its government has spend 25 million dollars on a major Royal Commission on New Reproductive Technologies (1989), yet it still remains without legislation. According to a Statistics Canada report, Canada has experienced a 35% increase in the frequency of multiple births from 1979 to 1999 (Canada. Statistics Canada: 2001). Like the US, the financial burden of the IVF procedure is placed on the consumer.

### Consequences of Self-Regulation in Canada

The Society of Obstetricians and Gynaecologists of Canada released in June 2008, voluntary guidelines on how Canadian doctors should manage multiple births. It advocates self-regulation for IVF practitioners, which would include limiting the number of embryos implanted in a woman at any one time (SOGC 2008). However, Dr. Barrett, chairman of the society's working group on multiple births suggests that 'Infertility clinics are very often self-run, self-regulated places'. He has seen mothers come from clinics with up to 10 embryos implanted (Barratt, 2000:3). There are no national or provincial controls of the number of embryos implanted. I was fortunate to be able to personally interview an obstetrician who specialises in multiple births about his opinions regarding IVF and multiple births and this interview is summarised in the appendix 11.

Fetal reduction has developed against this background. Multiple embryos are transferred and if there is evidence of more than two implantations, selective reduction is offered to the patient. In 1998, Doctor J. Pollard, acting head of maternal/fetal medicine at the University of Calgary, estimated that 50 to 100 women opt for selective reduction each year in Canada (Alberta Advisory Council, 1998:20).

Selective reductions were typically carried out for women pregnant with triplets or greater, where the risk of harm or death climbs sharply with each additional fetus. However Doctor Barratt advised more recently that there is a growing demand for reducing twins to one fuelled more by socio-economic imperatives than medical need, and raising vexing new ethical questions. He noted that even more medically necessary reductions could trigger lifelong angst and even threaten marriages (Barratt 2010). These reductions are largely avoidable through the adoption of SET and it is questionable whether parents should choose to terminate a fetus just because of the impact the child would have on their lives. I was unable to find comprehensive nationwide data for selective reduction. However one mother was quoted as saying that the Toronto doctor who she eventually found to perform her reduction performs several in a month (Blackwell 2010).

### **3.5 Canadian Background Research, Observations and Personal Experience**

In Canada, no clinic is required to disclose information regarding its activities so that data on multiple birth rates were not available for analysis. I have chosen to concentrate on observational data from Canada for this project. For some of the time that I worked on this thesis I lived in Toronto, Canada and gained some personal experience visiting IVF clinics. I am using this personal experience as background material for my investigation. My experiences contributed to the formation of my research intentions. Appendix 1 shows some material gathered in clinics illuminating costs and procedures at the time I was a patient. In the clinics I was able to talk to doctors and patients.

### 3.5.1 Clinician's Perspectives

Like the NHS of the UK, Canada has a comprehensive public health care system. I was able to interview an obstetrician who works out of a major public hospital in downtown Toronto. He is a member of the Society of Obstetricians and Gynaecologists of Canada's working group on multiple births. This doctor was sure that clinics implanted multiple embryos because of pressure from customers to show quick results. This was related to the high cost of the treatment. This doctor felt that regulation would be a positive measure for infertility patients in Canada. I also interviewed the director of a major private IVF clinic in downtown Toronto. All IVF clinics in Canada are privately managed. He strongly felt that legislation relating to IVF in Canada was not necessary. He felt that clinicians were in a unique position to cater treatment to the individual and that 'group consciousness develops in hospitals'. These interviews took place as part of background research and are summarised in appendix 11.

### 3.5.2 Attendance and Observations at Support Groups

Additionally I spent many months attending meetings at a professionally facilitated support group (also run out of downtown Toronto). I attended the meetings as a patient. This group was associated with a major IVF clinic and was organised for women who had become pregnant after infertility (appendix 12). These meetings provided many insights into the women's experience of IVF. It was during these meeting that my attention was brought to the issue of lack of transparency about information both of the actual procedure and its outcome and the lack of patient support offered during this extremely stressful treatment. I attended this group once a month and it was facilitated by a social worker employed to run the group by a fertility clinic. I disclosed my research interests to the group and achieved permission to use any information obtained for future research.

This facilitated support group focused on many issues surrounding infertility. It



served not only to inform and educate about infertility issues but also to explore underlying personal issues. In connection with infertility, these ranged from

- 1) alleviating the isolation often associated with infertility;
- 2) providing emotional support before, during and after treatment;
- 3) reducing stress and anxiety levels;
- 4) improving self-esteem;
- 5) exploring the emotional repercussions of infertility and attitudes related to pregnancy, child-birth and parenthood;
- 6) becoming knowledgeable about the social and legal aspects of building a family by donor egg and/or sperm, by surrogacy or by adoption, and considering the implications for all parties involved;
- 7) coming to terms with failure of treatment and facing the prospect of a life without children.

Additional aims were to address marital issues such as different coping styles and sexual dysfunction and to explore family-of-origin issues, which often arise during the infertility crisis.

There are many therapeutic advantages unique to groups. Infertility is often shrouded in secrecy and associated with shame and personal inadequacy. Having the opportunity to be part of a group with members facing the similar problems, sharing painful and confusing issues, as well as feelings of stigmatisation (often in the case of treatment with donor egg, sperm or embryo) is considered a tremendous relief (Wheeler, 1998). In this sense, group work breaks down social isolation and has a normalising effect (Thorn, 1998).

In addition I also attended a second support group. This fertility support group met every first Wednesday of the month and was for those who had finally conceived after struggling with infertility problems. I attended many meetings and felt comfortable as a 'member' of the group as I have had to overcome fertility issues myself. I explained to the group organiser, in front of the other members of the groups that my intention was to write a PhD thesis about IVF and multiple births. There was a verbal agreement that I could use any data gained for my research. The meetings were held from 6pm to 8pm. About 14 people attended each meeting and there were different faces each month. All were female and some brought infants. The focus of the discussion at the meetings was how to adjust to life with infertility, what this meant as a parent and the hardships that these parents were experiencing. All mothers had babies but did not know if they would be able to have a second baby. Many had experienced years of infertility treatment before finally conceiving.

Over the months I visited these groups I met many mothers who had conceived triplets as a result of their IVF treatment. I was able to discuss with them their experiences at the IVF clinics they attended in Toronto. I also discussed their various birth experiences and the aftercare they received at the hospitals where they delivered. Additionally I gained insights into the difficulties experienced in the home that come with caring for multiple infants. Difficulties started for the new parents of such multiples with often very complicated and stressful family care situations. Frequently premature infants were spending many, many early weeks of their lives in intensive care leaving parents without accommodation at the hospital at which their babies stayed. Hospitals just did not have the beds to accommodate the parents of the high number of babies they received in the intensive care unit. Babies were reported to be often miles from home due to shortage of space in intensive care at the parent's local hospital. Parents described their struggle to 'care' for the multiple infants whilst very often having other young children in the home to care for in addition to the newborns. Breastfeeding was described as particularly challenging in these circumstances and mothers reported 'camping' in hospital corridors for weeks to achieve this. More seriously, parents of multiples at

these support meetings reported infant health issues and deaths. Once home; parents lives were described as being completely overtaken by the demands of these multiple babies. This placed much strain on other family relationships. In addition there were often issues of space in the family home.

In summary, my comprehensive and varied experiences in Canada enabled me to talk to doctors, patients and other fertility workers in and out of the fertility clinic environment. Professional perspectives clarified treatment protocol, as it exists within an unregulated environment. A situation of no regulation clearly has huge effects on the multiple birth rates for clinic patients. Practices are shaped from this, and fetal reduction appears routine, as does clinician control regarding the number of embryos to transfer. The patients I spoke to were of particular and special value to this investigation and their opinions and insights allowed speculation about how regulation could improve their clinical experience. Regardless of whether they were parents of multiples or singletons the information I gleaned from these IVF patients led me to believe that transparency about clinical procedure and outcome to be vital in decreasing patient anxiety. It was also apparent that parents needed additional support in what was considered to be a commercial, and uncaring environment.

These patient opinions along with the results of studies about the outcomes of mental health support and fertility led my research to look at patient support as a way to improve the patient experience of IVF and the promotion of counselling as a forum for the patient to discuss the clinical process in depth. Support may be a tool to increase the viability of single embryo transfer, with counselling used as a way to clarify issues regarding elective single embryo transfer and promote this as a practical and attractive option. My discussions with the high number of patients that I was privileged to spend an immense amount of time with, due to the lengthy nature of IVF treatment guided my research for this investigation. It led me to focus on patient support and patient opinions in the UK, with particular attention to support and opinion surrounding SET. The patients that I met with made it clear

that the clinics that they received treatment at did not promote patient centred communication and that this was a barrier to effective treatment care.

## **CHAPTER FOUR**

### **BACKGROUND: INFERTILITY COUNSELLING**

#### **4.1 IVF and Psychological Support**

The following sections outlining psychological support and then more specifically counselling are fundamental to my overall study as my suggestion is that they are of absolute crucial importance to the IVF treatment experience.

Support for the individual patient on their journey through the IVF cycle and its various physical and emotional demands, has value on a superficial level in making a difficult treatment easier to navigate. However its value is far more significant than this. My proposition is that promoting the facility of counselling within the environment of the IVF clinic allows the opportunity for any patient to detach from the clinical processes of the treatment cycle. They are offered a space where they for the only time in their treatment are able to become autonomous and able to dissect and analyse the hurdles they face and their emotional and physical responses to these hurdles. In an institution where procedures are intrinsically medicalised and naturalised the facility of counsellor is an indispensable sanctuary. In the UK, public policy makes provision for counselling. However my investigation demonstrates that in practice this provision is inconsistent and limited.

Current literature surrounding patient experiences in the fertility clinic emphasise the intensely stressful nature of the procedure. This was confirmed by my personal experiences of the clinic and by my conversations and interactions with other IVF patients. I felt that psychological support was a necessary part of the treatment process and this next section explores this in greater detail.

## Psychological Impact of Infertility

The increasing global participation in fertility treatment has raised awareness and inspired investigation into the psychological ramifications of infertility. Researchers have looked into the psychological impact of infertility per se and of the prolonged exposure to intrusive treatments such as IVF on mood and wellbeing. This review has explored studies over the last 20 years that concentrate on women's participation in the IVF process, which monitor psychological symptoms and response to support mechanisms.

Parenthood is one of the major transitions in life for both men and women. The stress of trying to conceive unsuccessfully has been associated with emotional and psychological consequences such as anger, depression, anxiety, marital problems, sexual dysfunction, and social isolation (Nachtigall *et al.* 1992). In general, for infertile couples, women show higher levels than their partners on a global measure of psychiatric symptoms and subscales of anxiety, depression, hostility and cognitive disturbances, as well as on measures of stress and self-esteem (Wright 1991; Griel 1997). However, the male's responses to infertility increase when the infertility has been attributed to a male factor (Nachtigall *et al.* 2004). In this study women and their partners experienced a loss of identity and pronounced feelings of defectiveness and incompetence.

Stress, depression and anxiety are described as common consequences of infertility. A number of studies have found that the incidence of depression in infertile couples presenting for infertility treatment is significantly higher than in fertile controls, with prevalence estimates of major depression in the range of 15%-54% (Domar 1992; Demyttenaere 1998; Parikh 2000; Chen 2004). Lukse's study in 1999 found moderate to high levels of grief and depression before, during and after treatment. The study found that women resorted to individual coping behaviours such as self-talk and sleep. The study concluded that therapeutic counselling might be more effective if initiated before the IVF cycle. Levels of distress and coping strategies could be assessed at this time to provide patients opportunities to learn and practice new adaptive behaviours that could enhance

their ability to cope with the procedure and its outcome (Lukse 1999). Anxiety has also been shown to be significantly higher in infertile couples when compared to the general population, with 8%-28% of infertile couples reporting significant anxiety (Anderson 2003; Chen 2004; Parikh 2000). However, it may be noted that optimism has received little attention in the literature and has been found to be significantly affected by IVF treatment (Boivin 1996). Possibly, women embarking on a first course of IVF treatment may see the treatment as a first step towards the solution of their fertility difficulties and maybe a possibility to regain control over the fulfilment of a major life goal. This would be found to positively affect their emotional disposition.

The association between mood state and IVF treatment outcome has been assessed by many researchers. One study differentiates between what the researchers term as veterans and inductees: those with and without previous experience of IVF cycles. They found veterans to have 25% clinically elevated depression scores, compared to inductees with 15% clinically elevated depression scores. It was found that depressed women exhibited a lower pregnancy rate than non-depressed women (Thiering *et al.* 1995). This was confirmed in a later study, which also found depression levels to differ in women depending upon the extent of their experience with IVF. Women with a 2-3 year history of infertility had significantly higher depression scores compared with women with infertility durations of less than one year or more than 6 years (Domar *et al.* 1992). Researchers who discovered that distress levels in their study looked to be curvilinear again confirm these findings. The group in their study with a moderate amount of treatment failure experienced the most distress whereas distress level of those without or with a high amount of treatment failure experience was comparable (Boivin *et al.* 1995). Findings from these three studies provide support for infertility theories that suggest that infertility is a process rather than a series of independent emotional events and suggest that the distress and or depression women experience during infertility is a necessary part of their evolution towards acceptance of their infertility. Findings also suggest that the patients who have experienced a moderate number of IVF cycles may be in greater need of psychological intervention during the IVF process. Verhaak *et al.*'s study of

emotional adjustment to IVF revealed that when IVF resulted in pregnancy, negative emotions disappeared. This indicated that treatment induced stress is considerably related to threats of failure (Verhaak *et al.* 2007). Support during the IVF process should take this into account and provide the patient full information about failure and possible childlessness and strategies for emotional adjustment when accepting its likelihood in order to enhance a patient's control over their emotional response.

### Psychological Interventions

While many couples are experiencing high levels of psychological distress associated with cumulated attempts at unsuccessful conception before they approach and during the IVF process, the IVF procedure itself is also associated with increased levels of anxiety, depression and stress. Both baseline and procedural stress is thought to influence the efficiency of the IVF process (Klonoff-Cohen 2001). Throughout the course of the IVF cycle patients are often confronted with emotionally difficult choices such as whether or not to freeze embryos coupled with the high physical demands of the treatment: daily hormone injections, semen analysis, scans, and invasive procedures. The unpredictable outcome of the treatment itself is an additional major stress-inducing agent, likely to evoke feelings of depression (Dunkel-Schetter and Lobel, 1991).

Research in Israel has indicated that mood symptoms associated with IVF are not linked to hormones used to stimulate ovulation in the IVF patient but are influenced by other factors including the general stress of treatment. This study confirmed that the emotional response to the fertility treatment and the stress involved is a strong enough trigger to induce significant mood symptoms in many women, and this is irrespective of the short-term use of a GnRH-a hormone (Bloch 2011).

One UK study conducted in 1997 provides some insight into emotional assessment during the IVF cycle (Slade *et al.* 1997). Women were asked to complete emotional assessments at the time of pre-oocyte recovery and post-embryo replacement. There was found to be high anxiety and confusion before and during initial IVF



cycles. This may indicate the need for better pre-treatment information. Anxiety levels were also higher after embryo replacement increasing with failure of pregnancy and decreasing with success. The study recommended psychological support services for patients that recognised anxiety at intake and after failure of IVF. It was thought that high levels of confusion and bewilderment found during the initial cycle might indicate the need for better pre-treatment information. This was consistent with findings that I discovered through conversations with IVF patients at support groups in Canada (see Chapter five). It also supports a recommendation that would include a counselling/information session for every patient at the time of their initiation into the fertility treatment. The study recommended that services must recognise the presence of high anxiety at intake and provide psychological care for those identified as particularly distressed. Emotional difficulties after failure of IVF treatment can be considered to be iatrogenic effects, and psychological services should be provided to minimise any negative psychological consequences of treatment. This supports evidence from an earlier 3 year follow-up study by Slade that suggested that psychological functioning does not improve with time when there is continuing infertility. This was thought to be a possible result of several factors including male infertility influencing the male emotional state and particular coping strategies which were linked to negative emotional adjustment in women (Slade 1992). Counselling services may serve to minimise some of these effects.

Comprehensive, consistent knowledge about the course of the emotional responses through the various stages of the cycle treatment was unavailable. Most studies focus on the impact of failed IVF cycles. Hynes and colleagues assessed women at presentation for IVF and then following failure of IVF. They found women presenting for IVF were more depressed, had lower self-esteem and were less confident than a control group of fertile women and, after a failed IVF cycle, experienced a further lowering of self-esteem and an increase in depression relative to pre-treatment levels (Hynes *et al.* 1992). In a study by Verhaak *et al.* neuroticism, helplessness and marital dissatisfaction were underlined as risk factors for a couple's emotional response to a severe stressor like unsuccessful IVF treatment (Verhaak *et al.* 2005). This study lends credence to the proposition

of introducing counselling to the couple as a support mechanism before treatment begins. The counsellors who work at British clinics who I interviewed later in this research project felt that an informal session with a counsellor at the beginning of treatment could be particularly helpful in unifying patients' expectations of treatment before it starts. It was frequently commented upon by counsellors that each member of the couple had a 'differing agenda' when embarking on treatment. Another study looked at relationships between attachment, appraisal, coping and adjustment in men and women experiencing infertility concerns. This study found that men and women's perception of infertility were different. Men's perception centred on how infertility as a condition presented a threat to their sense of masculine self and women's perception focused on a sense of loss (Bayley *et al.* 2009). They concluded that offering counselling to couples at the treatment stage may be too late as the findings of their study suggests that early intervention should be considered. Although it is likely that brief therapy will not offer most clients an adequate opportunity to alter their basic attachment patterns, a more realistic aim in short-term work may be to help the client make connections related to how their attachment may be associated with particularly unhelpful coping patterns (Wei *et al.* 2003). This study supports the notion of an informal meeting for counsellors with all potential IVF patients to identify specific needs.

In 2005 a study by Verhaak and colleagues, drew attention to the notions of acceptance and perceived social support as protective factors in the development of anxiety and depression after unsuccessful IVF treatment (Verhaak *et al.* 2005). These could be taken into consideration when proposing support for IVF patients. A recent study in Sweden discovered that life quality measures were lower for both male and female patients of unsuccessful IVF and that both partners suffered bereavement and frustration when compared to successful patients (Johansson 2010). Other studies concern factors contributing to dropout from IVF. A significant number of dropouts are due to psychological factors, although cost has also been cited as a reason for discontinuing treatment (Domar 2004; Hammarberg *et al.* 2001). A British study undertaken at Ninewells Hospital, Dundee reported lack of success 23% and psychological stress 36%, as factors quoted by couples as the reason influencing the decision to discontinue treatment. It was also found

that these two factors were very strongly associated, both being reported by 18% of couples with a reciprocal increase in those quoting lack of success and psychological stress as reasons for discontinuation with increasing number of attempts (Rajkhowa *et al.* 2006). This supports findings in Sweden in 2004 where a majority of discontinuations were due to psychological stress (Olivius *et al.* 2004).

The outcome of IVF may also be influenced by psychological factors. Studies which address this issue are also of particular interest to my thesis as I hypothesise that psychological support for patients may be an important part of adopting SET transfer in IVF clinics in the UK. Support in the form of counselling can provide a forum to examine elective single embryo transfer in detail for each patient. Increasing counselling as a mode of support in clinics may also provide a decrease in distress, stress and anxiety, which may influence IVF success rates in some patients.

A number of studies have examined stress and mood state as predictors of outcome in IVF. The majority of these studies support the theory that distress is associated with lower pregnancy rates among women pursuing infertility treatment. In a Dutch study conducted in 2001, there was found to be a significant relationship between baseline psychological factors and the probability to becoming pregnant after IVF, controlling for other factors. Pre-existing psychological factors were independently related to the treatment outcome and therefore should be a focus of patient support during IVF. These psychological factors may be improved by intervention (Smeenk *et al.* 2001). A Canadian study asked women to complete a daily stress rating for a complete IVF cycle. The women who failed to become pregnant reported more stress. The differences between the pregnant group and non-pregnant group indicated that stress was related to IVF outcome. Certain data suggested that negative feedback communicated to patients responding poorly to IVF in the non-pregnant group may have increased their stress level (Boivin 1995). The faculty of Psychology at UNED University in Madrid, in discussing the proposition that IVF treatment should start with reducing stress, pointed out that the psychological disposition of both parents-to-be influences their fertility and that reducing stress before the IVF program may improve the efficacy of the technique

and prepare the couple for initial or subsequent failures (Campagne *et al.* 2006). Two studies disputed a relationship between stress and IVF outcome (Eijkeman 2009, Boivin 2011). These studies were both confined to induction patients in their first IVF cycle and it could be at this time patients are significantly influenced by optimism. The measurement of stress in both studies was 'state anxiety' which may be a limited and superficial estimate of stress. All studies indicate those stress and treatment outcomes are complex in their relationship. Many factors will influence any individual in treatment. These factors include the patient's complicated individual circumstances and the length of their time in treatment.

In the light of research suggesting that psychological symptoms may interfere with fertility, success of infertility treatment, and the ability to tolerate ongoing treatment, interest in addressing these issues during infertility treatment has grown. Several studies suggest that cognitive behavioural group psychotherapy and support groups, decrease stress and mood symptoms as well as increase fertility rates. In a study by Domar of 52 infertile women, a 10-week group behavioural treatment program significantly reduced anxiety, depression and anger. It was concluded that behavioural treatment is associated with significant decreases in negative psychological symptoms (Domar *et al.* 1992). In a year-long follow-up study, Domar compared pregnancy rates of women undergoing IVF who were randomised to group cognitive behavioural therapy designed to decrease depression and anxiety, a support group, or to no group treatment. Visible pregnancy rates were 55% for the cognitive behavioural group, 54% for the support group and 20% for the controls (Domar *et al.* 2000). Cognitive-behavioural treatment was additionally shown to reduce cardiovascular response to stress in IVF patients (Facchinetti *et al.* 2004). In a Turkish study where the intervention group received couple counselling directed towards education and addressing stress throughout their IVF cycle with a guide developed for the couples and much educational material in support of counselling and the control group received only routine medical care, the intervention patients had a lower anxiety and depression score, in addition to significantly higher pregnancy rates (Terzioglu 2001). The benefits of psychotherapy have been demonstrated by a study by de Liz *et al.* that showed that psychotherapy accompanying IVF treatment yielded similar

conception success rates to psychological interventions administered to patients not in specific care (de Liz *et al.*, 2005). A body-mind group intervention program for infertile couples, which integrated concepts and techniques from body orientated therapy, art therapy and multi-family therapy has also shown promising results when used as a marital group intervention at the Leuven University Fertility Centre (Lemmens *et al.* 2004). This has been recently confirmed in 2011 by Domar *et al.* whereby IVF patients enrolled on a mind/body support program before their first round of treatment showed significantly higher pregnancy success than those who were not (Domar *et al.* 2011).

Although there have been few systematic studies in infertile women undergoing IVF examining other types of support such as education and skills training, relaxation methods, acupuncture, pharmacotherapy or other methods of support, treatments that decrease psychiatric symptoms and stress in the general population will likely benefit this population. A recent experiment conducted in an IVF clinic in Israel discovered that a 15-minute session of clown entertainment impacted IVF success. This experimental prospective quasi-randomised study examined the impact of a medical clowning encounter after embryo transfer (ET) in IVF and found that the pregnancy rate in the intervention group was 36.4%, compared with 20.2% in the control group (adjusted odds ratio, 2.67; 95% confidence interval, 1.36–5.24). Medical clowning as an adjunct to IVF-ET may have a beneficial effect on pregnancy rates and therefore was considered to deserve further investigation (Friedler *et al.* 2011). In 2008 researchers found that acupuncture given as a complement to IVF increased the odds of achieving pregnancy. According to the researchers, the results indicate that 10 women undergoing IVF would need to be treated with acupuncture to bring about one additional pregnancy (Manheime *et al.* 2008). The results, published in the British Medical journal were considered preliminary but point to a potential complementary treatment that may improve the success of IVF and the need to conduct additional clinical trials to confirm these findings.

In summary, this research clarifies and confirms the presence of stress and distress as experienced by infertility patients. These symptoms arise from a

complex mixture of sources. The infertility patients are likely to experience stress as a result of unsuccessfully trying to conceive before embarking on treatment. This may be magnified for many by socially constructed perceptions of motherhood and family roles. On entering treatment stress and distress may occur as a reaction to clinical practices. Some studies suggest that this response may actually influence the outcome of treatment. From this perspective, the promotion of support services in IVF clinics in the UK can only have a productive and beneficial outcome. Benefits of support, especially in the form of in-depth counselling support may hold a myriad of different purposes and advantages for any one patient. For the purpose of this investigation I will focus on patient support and the benefit it may be to any one patient to clarify the procedure of SET and its likely outcomes.

#### **4.2 IVF and Counselling**

**It is apparent from the literature that psychological support mechanisms can have many benefits for a patient undergoing treatment. My investigation is aimed at policy analysis pertaining to IVF in the UK. I next conduct an overview of counselling, as this is the most prolific medium of support offered in UK clinics. My aim is to ascertain whether counselling may incorporate the UK policy mandate to decrease IVF multiple births.**

In attempting to analyse the role of the counsellor within the context of the IVF clinic it can be useful to pause to contemplate some of the processes that have contributed towards the medicalisation of infertility and its subsequent confinement to the sterile clinical environment whereby the patient is not treated for her condition but instead opts to engage with a clinical intervention which may or may not circumvent her condition. During the last two decades great advances have been made in the field of ART. Treatments such as IVF, ICSI, and IVF involving donor gametes and surrogacy have given new choices to many infertile patients. These new technologies engage cultural meanings of fertility and in doing so challenge traditional attitudes towards, gender, sexuality and the family unit. Previously taken for granted fundamental aspects of everyday life have been

subjected towards new scrutiny. Becker draws our attention to what new reproductive technology means for gender identity in her unique research. Her findings are sociologically intriguing because we see that the technologies both reinforce gendered patterns of power and authority and at the same time serve out a 'vehicle for living out the patients goals' (Becker 2000:28). Therefore gender identity is both reaffirmed through the technology but may also be maintained and expanded. Becker illuminates a cultural ideology of 'normalcy' throughout this book (Becker 2000:34). She explains that biological parenthood is closely tied to Americans' notions of what is normal. However we need to acknowledge that these technologies are segregating that normalcy to the white middle classes.

The highly developed medical field of reproductive assistance for those who have access to it has led to what Becker describes as the 'medicalisation' of infertility. Becker feels that the medicalisation of infertility stems from deeply rooted cultural phenomena that contribute to the social reproduction of disease. With regards to fertility its medicalisation has produced a public pronouncement that it is abnormal not to be able to reproduce biologically. Social science literature of the 1960s and 1970s addressed involuntary childlessness as a social condition. As infertility influenced a greater population due to delaying choice of childbearing there was a shift in perspective to an increased emphasis upon a medical perspective. Becker and Nachtigall set out to examine this perspective by conducting comprehensive interviews in fertility clinics. Their findings were that: 1) Treatments are highly intrusive 2) they focused the cultural concept of abnormality regarding fertility upon the body of the individual: their bodies had become unpredictable, and 3) patients suffered cumulative emotional effects (Becker and Nachtigall 2008). In summary, they found that patients' feelings of abnormality intensified with treatment, as expectations of cure were not realised. The treatment proved problematic because cultural norms with regard to reproduction were reflected and endorsed within it. Fertility treatment can be viewed as a perpetuation towards the medicalisation of life, which in turn limits freedom of choices for the individual.

The above study confirms an earlier study whereby Becker and Nachtigall interviewed fertility patients about the risks they were prepared to accept whilst

undergoing fertility treatment. This research suggests that once infertility is medically designated as a disease, both patients and practitioners pursue a 'cure' through a well-delineated pattern of medical treatment, despite the risks of such treatment and independent of the likelihood of success. When medical views of risk and responsibility are teamed with women's persistence in the pursuit of a pregnancy, medical treatment may be taken to extremes. Americans consider risk-taking to be their prerogative when personal histories reflect strong cultural mandates about norms, values, rights, and responsibilities, and these in turn are interpreted as health-related by both consumers and health professionals. As a consequence, the forces that trigger medicalisation are activated and medical technology is given potentially limitless scope (Becker and Nachtigall 1994).

With powerful forces at play that are inherent in the medicalisation process there is a danger that the emotional impact of infertility is neglected and that the problem is reduced to a biological or medical one. This limits the scope of support and help available to the infertile patient. Counselling psychology in the UK has evolved from the disciplines of psychology, sociology and philosophy, but more slowly than its counterpart in the USA (Cowie 2007). Counselling is a notoriously imprecise term, used to describe a wide range of functions and performed by an equally wide range of individuals (Blyth, 1995). However in the UK, infertility counselling has become formalised and structured due to the formation of the British Association of Infertility Counsellors (BICA) in 1998. This is a professional organisation for infertility counsellors and offers training, guidance and guidelines. A formal definition of counselling would be that it was "an interpersonal process, based on a theoretical framework, which is used to bring about change in a skilled and systematic way" (Daniels 1999: 25). The BAC (British Association of Counsellors) has described counselling as a place where individuals can be given an "opportunity to explore, discover and clarify ways of living more satisfyingly and resourcefully" (BAC 1984: 9). However, counselling with infertile individuals is often also about support and the clarification of life goals. Thus counselling definitions may focus on counselling as a context for support, advice and guidance rather than as a vehicle for change (Applegarth, 1999). Regardless of the precise definition the term 'counselling' is considered to be an entity which requires



professional qualification and which differs from patient-centred care. Patient-centred care is the psychosocial care provided as part of routine services in the clinic. It is an approach to care which is expected from all members of the medical team at all times. Patient-centred care aims to facilitate communication processes between staff and patients and aims to ensure that the people being treated are understood as individuals and not only as bio-logical entities. Patient-centred care is desirable and may provide a good basic relationship from which the patient may then feel comfortable seeking support and/or initiating counselling. In many countries (e.g., Germany, Switzerland) patient-centred care is more formally integrated in medical treatment through the application of psychosomatic or psychosocial models, which propose that the person who treats (e.g., doctor, nurse) integrates both medical and emotional care in their exchanges with patients (Bundesärztekammer, 1998).

Infertility Counselling takes on 3 overlapping forms: Information and Implications, Support and Therapeutic. Providing sufficient information about the medical aspects of the treatment is primarily the responsibility of the medical doctor. However, patients consult counsellors to obtain more information concerning the social and emotional implications of the infertility treatment. It is often the task of the counsellor to help the individual collate and make sense of all the information to be considered when making a decision related to treatment and parenting options. Implications counselling aims to enable the person or people concerned to understand the implications of the proposed course of action for themselves, for their family and for any children born as a result. Implications counselling would be an appropriate forum for patients to discuss issues surrounding single embryo transfer and the implications of adopting the technique in their fertility treatment. Support counselling aims to give emotional support to patients experiencing distress. Within infertility, there is often a natural progression from support counselling to therapeutic counselling. Several models of therapeutic counselling have been developed over recent years (e.g. Hammer Burns & Covington, 2006; Strauss, 2001) providing a wide variety of counselling modalities (e.g. individual, couple or group) and intervention strategies.

In the UK, the latest guidelines issued by BICA were in 2012. The Guidelines for practice are divided into eleven sections: 1. What is counselling 2. Good Quality of Care 3. Regulatory Framework 4. Counselling for infertility and assisted conception 5. Welfare of the Child Assessment 6. Gamete/Embryo Donation, egg/sperm-sharing or surrogacy 7. Counselling for people who travel overseas for treatment 8. Fertility Preservation 9. Pre-Implantation Genetic Diagnosis (PGD), HLA and other genetic counselling 10. Qualifications, Training and Accreditation 11. Quality Management (BICA 2012). Guidelines specifically referring to multiple births can be found in section 7 of the guidelines, aimed at those travelling overseas for treatment and state 'that any patient should find out 'the policy of the clinic on number of embryos transferred and risks of multiple pregnancy' (BICA 2012).

In the UK it is clear that counselling has the potential to be used more thoroughly as a tool to comprehensively incorporate any clinic's mandate to reduce its multiple birth rate. Much research supports the need for pre-treatment counselling to inform and stimulate discussion about all aspects of the infertility treatment process including SET. One study demonstrated an increased psychosocial risk associated with each increase in birth multiplicity (i.e., singleton, twin, triplet) resulting from assisted reproduction. They found that for each additional multiple birth child, the odds of having difficulty meeting basic material needs more than tripled and the odds of lower quality of life and increased social stigma more than doubled. Each increase in multiplicity was also associated with increased risks of maternal depression. The study concluded that to increase patients' informed decision-making, assisted reproduction providers might consider incorporating a discussion of these risks with all patients before they begin fertility treatment, and holding the discussion again if the treatment results in a multiple gestation (Ellison *et al.* 2005). These data emphasise the need for IVF providers to identify appropriate counselling, depression screening, and supports for patients before, and if necessary after, multiple births.

Other research supports exposure to a counsellor or counselling team before fertility treatment. One research project suggested that a referral to a counsellor, after initial embarkment on the course of fertility treatment, might cause problems

for some patients. Patients may interpret referral as rejection on the part of the physician and may feel they have been “passed on”. Such a referral may hurt a patient’s feelings, especially if medical treatment has been unsuccessful. Because of this, involvement of counsellors should always be integrated into patient care from first consultations and presented to couples in a positive light (Boivin *et al.* 1999). Another study analysed a model of routine pre-IVF counselling focusing on the narrative capacities of couples. This type of pre-treatment assistance was acknowledged to be an acceptable form of psychological assistance for pre-IVF couples (Emery *et al.* 2003). More recently, one study has assessed preparatory psychosocial counselling prior to participation in medically assisted reproduction. It was discovered that clinics should not assume that patients could accurately judge the benefits of counselling before actually engaging in the session. Identifying patients most likely to benefit and providing a clear rationale may further increase receptivity to a proactive counselling service (Hakim *et al.* 2004). These findings all suggest that pre-treatment counselling may incorporate discussion of single-embryo transfer as well as offering other benefits such as psychological assistance, technical explanations and discussing relationships.

Using counselling as part of a clinic’s mandate to reduce multiple births in the UK allows the patient to consider the processes involved outside of the clinical process. Couples need to be provided with a realistic picture of what it would be like to parent more than one child of an identical age and be provided with information about the health, emotional and financial consequences for them and their immediate family. The work of the counsellor in this respect is very difficult. Time can be dedicated to the process of giving full information and allowing for exploration and discussion of issues in a manner that may not be possible with the clinician. A documented typical reaction of infertile partnerships when they are exposed to the idea of a multiple pregnancy is that they are euphoric and make the comment, “That would be a ready-made family” (Murdoch 1997). In a postal survey of an undisclosed number of UK patients, Murdoch received 150 replies to a question asking the ‘ideal outcome of IVF treatment; one, two or three babies?’. Forty-five per cent of respondents considered multiple pregnancy an ideal outcome, whilst 31% desired a single child and 24% either one or two babies. In an

American survey of patients' attitudes about the number of embryos to transfer  
Gleicher and colleagues mailed a questionnaire to 3800 unselected couples with infertility problems achieving a 15% response rate. They found that 69% of couples who responded felt a multiple pregnancy would be the ideal outcome of IVF. They certainly did not see it as a problem (Gleicher *et al.* 1995).

A central aspect of fertility treatment is the exposure of the patient to failure. This relates directly to the phenomena of aggressive multiple embryo transfer techniques and the multiple births that result from them. Due to the high failure rate of IVF as a technology, more than one embryo has very often routinely been introduced to any female patient in the hope to increase the success of any individual procedure. These techniques have become adopted in an attempt to boost a fertility treatment that is largely unsuccessful. Physicians and couples generally consider successful treatment of infertility to mean achieving pregnancy and the birth of a child. Pregnancy after infertility is a unique pregnancy and has different stress and emotional and physical adaption patterns to a naturally conceived pregnancy. Consequently infertility counsellors need to be available to support both success and failure. In part 25 of their handbook for clinicians, Covington and Burns provide valuable advice about counselling guidelines for this very unique type of pregnancy (Covington and Burns 2006).

However success can also mean that not having children is accepted and/or that couples are enabled to see their childlessness from another perspective which allows them to reshape their lives and achieve life satisfaction (de Parsevale, 1992; Kemeter, 1998). The counselling and support team at a fertility clinic may have a vital role in creating this alternative model of success. More couples will be exposed to this possibility after treatment than the possibility of achieving a live birth. The medicalisation of infertility, well documented by Becker (2000:39) means that the clinic may readily focus only on medical procedure and the spectacular achievements of the progress of science. However, only by including the psychosocial dimension into the infertility consultation will the fertility clinic be able to make biological reproduction human reproduction. The basic aim of any counselling is to ensure that patients understand the implications of their treatment

choice, receive sufficient emotional support and can cope in a healthy way with the consequences of the infertility experience. A more holistic approach to patient care is believed to improve health outcomes, increase patient and team satisfaction, reduce negative psychosocial reactions and help patients better come to terms with their experiences.

To be infertile involves experiencing the psychological trauma of childlessness as a result of its perceived undesirability. My investigation proposes that for public health policy surrounding IVF to be fully effective that, in addition to the necessary medical procedures, it should also focus on the patients' psychosocial and emotional needs. Clinics need to provide an environment that offers a comprehensive understanding of childlessness. This can be practically administered by giving all patients the appropriate information about the procedures available and ensuring it is processed, and offering comprehensive counselling and other support services. Infertility counsellors have always been, and many still are, relatively isolated in their practice-in many centres working without the close support of other specialist counsellors, since they are employed part-time or are contracted to provide off-site services, while full integration into the clinics' multi-disciplinary teams has been slow to develop (Blyth 2008). The counsellors who I interviewed for this investigation were of the opinion that caring for the emotional needs of the patient demands continuity and should not be treated as a single event; it also needs to be endorsed by the clinic as a team and not just by more psychosocially orientated staff members.

#### 4.2.1 Statutory Requirement for Counselling in the UK

Infertility counselling is mandated in the United Kingdom under the Human Fertilisation and Embryology Act 1990, as amended by the Human Fertilisation and Embryology Act 2008. All medical centres offering fertility treatments must provide access to a qualified infertility counsellor (HFEA 2009). Counselling was first recommended by the Report of the Committee of Inquiry into Human Fertilisation

and Embryology in 1984 (Warnock Report). The report recommended that 'counselling should be available to all infertile couples and third parties at any stage of the treatment' (Warnock 1994:16). A closer look at the report in full gives further details of the type of counselling, information and discussion envisioned. It acknowledges that many of the 'problems which may arise in the course of treatment, whether this treatment ends in the birth of a child or not, are complex and they need to be given careful consideration over a period of time. We therefore believe that counselling should be available for infertile couples and for donors. In particular the task of the doctor and the counsellor must be to ensure that couples and donors fully understand the implications of what they are embarking on, what rights and duties they may have, and where they may expect to experience difficulties' (Warnock 1994: 16, s.3.3). This section clarifies the priority placed upon donors and recipients of gametes during the IVF transaction. The report later lays the framework for such counselling and suggests that it 'is essentially non-directional. It is aimed at helping individuals to understand their situation and to make their own decisions about what steps should be taken next. Counselling need not necessarily take place at the hospital, though this may be the most convenient location. It should be carried out in a neutral atmosphere and involve a skilled, fully trained counsellor. We recommend that counselling should be available to all infertile couples and third parties at any stage of the treatment, both as an integral part of National Health Service provision and in the private sector. We recognise that there may not be sufficient counsellors trained in this field at present, but we feel it is possible for counsellors trained in other fields to adapt their skills to deal with infertility. Specialised further training and funding for those attending such courses will need to be made available. We look to training bodies in social work and counselling to give guidance on these training needs and how they should be met' (Warnock 1994: 16, s.3.4). BICA was later formed in 1988 to support the needs of the counselling professionals as recommended by the Warnock Committee. This section clarifies the need for the availability of counselling at all stages of the fertility treatment, regardless of whether the treatment facility is private or NHS.

#### 4.2.2 British Infertility Counselling Association (BICA)

Credentialing for fertility counsellors is available through the BICA. Information about accreditation is available from [www.bica.net](http://www.bica.net). All infertility counsellors I spoke to during my research were accredited with BICA and a summary of my investigation was published in their professional journal: *Journal of Fertility Counselling*, in the Spring edition 2011. However it is important to note that the offer of counselling has to legally be made but patients do not have to accept the offer of counselling to receive treatment. The law only requires counselling to be *offered* when any individual or couple seeks treatment that will create embryos in vitro (HFEA 2009).

However, added emphasis is placed on the need for counselling when donor gametes are used and implications' counselling in this situation is to be performed separately from any counselling surrounding the implications arising from the creation of embryos in vitro. Section 3 of the HFEA 8<sup>th</sup> code of practice clarifies this. The code gives an interpretation of mandatory requirements and states that "If the possibility of treatment with donated gametes or embryos arises, the centre should offer counselling about the implications of treatment with donated material separately from counselling about the implications of treatment in general and before treatment with donor gametes starts" (HFEA 2009). This would also be the case in other more complex legally permitted situations such as in the case of both traditional and gestational surrogacy.

Section 11 of the HFEA 8<sup>th</sup> code of practice clarifies counselling requirements for those donating gametes. Again, the code gives an interpretation of mandatory requirements and states, "All prospective donors must be given a suitable opportunity to receive proper counselling. Where embryos are to be donated, the recruiting centre must offer counselling to each person whose gametes were used to create the embryos" (HFEA 2009). Also, if the possibility of donating gametes or embryos for the treatment of others, or for research or training, arises during the

course of treatment, the centre should allow potential donors enough time to consider the implications and to receive counselling before giving consent (HFEA 2009).

BICA was founded in 1988 as an independent association and registered charity that 'aims to encourage and facilitate its members to provide the highest standards of counselling support to people affected by fertility issues'. BICA draws its membership from a wide professional field, including social workers, psychologists, nurses, and others, and represents most of those offering counselling services at licensed fertility clinics. Since its inception BICA has assumed an increasingly active role in the development of assisted conception services in the UK. It is in regular communication with the department of health, the HFEA, and the multidisciplinary British Fertility Society (BFS). BICA has participated in policy consultations undertaken by the HFEA, the government and the UK parliament. As an organisation, it offers extensive membership information and support. There is a practice guide series and Journal of Infertility Counselling published regularly. Further professional development for members is provided through national and regional meetings, conferences and study days. Information for members and the public is available through an information officer and a website that also provides access to a nationwide infertility counsellor referral system. Despite the active role of BICA in fertility treatment it is important to mention that although the credentialing of fertility counsellors is available through BICA, it is not required. The HFEA in 1991 recommended that the minimum qualifications required for a counsellor be a certification of qualification of Social Work or an accreditation by the British Association of Counselling or Chartered Psychologist status (UK: Human Fertilisation and Embryology Act 1990). These requirements have been updated in the HFEA latest 8<sup>th</sup> edition code of practice. It is required that treatment centres should ensure that at least one individual is appointed to fulfil the role of counsellor. All counsellors should have specialist competence in infertility counselling and hold a recognised counselling, clinical psychology, counselling psychology or psychotherapy qualification to the level of diploma of higher education or above, and be accredited under the scheme of the British Infertility Counselling Association (or an equivalent body), or show evidence of working



towards such accreditation (HFEA 2009). The HFEA will be issuing a new Code of Practice guidance, which will come into force on 1 October 2013. No changes to counselling credentialing have been made.

However, even in the UK, where legislation promotes fertility counselling, my research has shown wide variations between clinics with regard to accessibility, standards and the provision of counselling services, not to mention 'interpretation' of the legislation to fit the specific clinic's biases about infertility counselling or counselling in general. Also the vast majority of infertility counsellors are female, raising the potential issue of gender barriers for male clients. This would appear to contribute to other sectors of gender bias in the UK for 'helping/caring' professions.

In 1995 one study attempted to evaluate the support and counselling services made available by the licensed units in the UK (Hernon *et al.* 1995). This was done in the form of a questionnaire to IVF units in the UK, from both the private and National Health Service sectors. Of these, 95% have their own counsellor, most of whom (84%) practised on the premises. One-third of these counsellors had a dual role, mainly as nurses, social workers or in administration; 98.6% were trained in counselling, with only 28% having either the Certificate or Diploma in Counselling. One-third (32.2%) of centres charged for counselling, with only 13 units indicating their charges. The majority of centres (78.8%) do not actively follow-up patients after counselling and one-quarter (25.5%) did not have a specific counselling room. Over two-thirds (68.4%) of centres described their clinic support network as inadequate. The results of this survey suggest that, although the requirements of the HFEA Code of Practice are being adhered to reasonably well, overall patient uptake of counselling was low and counselling provision could be improved. These findings were confirmed by my interviews with counsellors in 2010 (Chapter 7). The potential benefits of counselling are well documented, and therefore all workers in the field of reproductive medicine need to place additional emphasis on the possible advantages of counselling in an effort to improve uptake.

#### 4.2.3 Infertility Counselling: A Global Perspective

Currently there are no international guidelines for infertility counsellors. This has been investigated recently by Blyth (2012). He conducted an analysis of formal guidelines produced by 7 national infertility-counselling bodies. Although no formal international guidelines are yet established, key trends in practices were identifiable. Blyth observed that counselling across borders could be analysed in four broad areas. This analysis was conducted upon the basis of legal mandate, credentials for counsellors, forms of counselling and its association to specific places in the course of treatment. In conclusion it was found that, internationally, the development of infertility guidelines is best described as a 'work in progress', although key trends were evident (Blyth 2012). This study indicates a potential for organising international guidelines by bodies such as ESHRE. These would be of particular benefit to small countries with a limited clinic and counsellor population.

Currently in Europe the provision of counselling for infertility patients largely depends upon whether or not a country has legislation regarding assisted conception and if so does the legislation refer to counselling. ESHRE founded a Psychology and Counselling Special Interest Group in 1993. The group's purpose is to address the psychosocial issues and needs of clients and professionals working in infertility. The group conducts research and authors ESHRE's Counselling Guidelines. Currently Germany, Spain and Switzerland must offer counselling to patients undergoing fertility treatment. Spain and Switzerland both offer formal regulatory backing for infertility counselling (Blyth 2012). However, guidelines are more vague than for the U.K. and fewer infertility clinics employ designated fertility counsellors in all three countries (ESHRE: 2001).

In the United States, the American Society for Reproductive Medicine (ASRM) established a Mental Health Professional Group in 1995. Membership is open to all active members of ASRM, and in 2005, membership was 348 individuals (ASRM 2004:20-21). In the US, there is no national or state policy related to assisted conception, and consequently there is no requirement for fertility clinics to

provide or recommend counselling. The ASRM has various guidelines recommending that counselling services be available in programs offering assisted conception procedures (ASRM 2004:18-19). However, adherence to these recommendations is voluntary on the part of the clinics.

In Canada regulations about mandatory counselling were proposed under the Human Reproduction Act 2004. Consultations were held with Health Canada, counsellors, consumer groups and other stakeholders. In 2006 the Canadian Infertility Counselling Association (CICA) was developed (Canada, Health Canada: 2010). However, the federal government's attempts to prescribe counselling requirements (along with other measures to regulate ART nationally) were struck down by Canada's Supreme Court in December 2010 on the grounds that they violated provincial government powers (Supreme Court of Canada, 2010).

In New Zealand and Australia counselling is required to be made available in a number of jurisdictions in relation to specific elements of ART provision. Despite regional variations on provision, service providers in this area all fall into the accreditation system administered by the Reproductive Technology Accreditation Committee (RTAC) of the multi-disciplinary professional body, the Fertility Society of Australia, whose remit also includes New Zealand (Blyth 2012).

#### 4.2.4 Infertility Counselling and Multiple Births

The economic, social, psychosocial and health costs of multiple pregnancies are great and prevention is the most important means of decreasing multiple gestations. Couples need assistance in understanding the risks involved in transferring more than one embryo during any one IVF cycle and counselling may be a forum for conveying and understanding such risks. The latest research from the HFEA attempts to evaluate the first year (2009) of its new multiple births policy. Findings suggest that all patients desire face-to-face discussion in the clinic before treatment started SET. Also, more than two thirds of patients look for more information about SET outside of information from the clinicians and found support groups, counselling and discussion forums helpful with this (HFEA: 2010). It is

important for infertility clinics to provide the largest amount of information possible regarding multiple birth risks as research shows that patients may significantly underestimate the risks associated with a prospective multiple birth in their decision regarding how many embryos to transfer. They are likely to respond to the prospect of a multiple pregnancy with delight and without apprehension (Newton *et al.* 2007). One study found that the longer term infertile patient displayed significantly more positive attitudes about the prospect of a multiple gestation than the newly infertile control group (Leiblum *et al.* 1990). This study suggests that evidence relating to multiple pregnancy risks needs to be carefully organised around the needs of each individual patient. The counselling forum may provide a complete and ideal opportunity for such discussion.

One study in 2007 has examined which issues concerning multiple pregnancy should be focused on during counselling (Emery 2007). The study asserted that primary prevention is the best way to reduce multiple births. It found that for preventative psychosocial counselling, some centres employ counsellors, but if not, this becomes the physician's task. It was felt that an in-depth assessment was required to define how many embryos to transfer and what risk of multiple birth is acceptable to patients. Counselling should address the following: the relationship between pregnancy rate, multiple pregnancy rate and the number of embryos transferred; benefits and risks of multiple pregnancy; and possibilities for primary and secondary prevention. The research suggested that patients should voice how they feel facing these issues; which issues are worrisome; how they anticipate these possibilities; and what psychosocial support exists that could be mobilised. In summary, the research asserts that psychosocial counselling reinforces the partnership between couples and the assisted reproductive technology team, allowing for primary prevention and informed consent on multiple pregnancy issues.

Research for this chapter demonstrates that the mechanisms for counselling are statutorily in place at IVF clinics. Feedback to the HFEA has demonstrated that aside from financial concerns patients were most likely to be influenced to embark on SET when given consistent face-to-face information about its benefits by all

staff at the clinic (see chapter three). Patients clearly desire a forum to discuss the full implications of SET as most still feel it reduces their chance of a successful pregnancy. The following research investigates the counselling space as a forum for such discussion within the clinic setting.

## **CHAPTER FIVE**

### **LITERATURE REVIEW**

**A brief synopsis of the emergence of multiple embryo transfer/ multiple pregnancy/multiple birth in relation to IVF as a social problem and a proposed social policy resolution.**

#### **5.1 Multiple Births: A Social Problem**

Iatrogenic twins and higher order multiples have mortality rates that are well in excess of rates in singletons. For this reason alone the position of this study is that wherever possible iatrogenic multiple conceptions should be avoided and that IVF clinics in the UK should consider moving towards a policy of single embryo transfer. There are additional complications aside from mortality associated with twins and higher order multiples that include health risks for the twins and their mothers and psychosocial risks for the immediate family (RCOG 2012).

Natural fluctuations in the incidence of twins are associated with the occurrence of non-identical twins. The incidence of identical twins has been fairly consistent around the world. The incidence of identical twins falls at around 1/300 births globally. The incidence of non- identical twins is variable globally. Ranging from 1/11 in the Yoruba tribe in Nigeria, 1/100 among Caucasians to 1/250 in Orientals (Chitayat and Hall 2006). In the last few decades the global incidence of twins has risen due to the widespread use of reproductive technology. IVF has greatly impacted the incidence of non-identical twins because more than one embryo is transferred. However there is a 2-5 times increase in identical live born twins in pregnancies conceived by IVF. This may be a 'result of breaks in the zona pellucida caused by handling, the media used, use of ICSI, zona hardening relating to ageing, the drugs used or the underlying causes of infertility' (Chaitayat and Hall

2006:92).

It is clear from Swedish evidence that legislation and public policy can have an important role in changing IVF practice to encompass SET. Sweden has dramatically reduced twin rates without detriment to pregnancy rates. (Olofsson *et al.* 2004). This has been backed up by a qualitative study that suggests that, while many couples undergoing IVF do not have a preference for eSET, they would comply with any law enforcing SET (Porter & Bhattacharya 2005). IVF patients have demonstrated that they very often view a multiple pregnancy as desirable (Gleicher *et al.* 1995). My interaction with IVF patients has demonstrated that sometimes this is because patients who are paying a high cost for their treatment feel that having twins may be a cost-effective use of IVF treatment. Other times patients may be of the opinion that they would prefer a multiple embryo transfer, as they believe that this will maximise the chance of a live birth at their first attempt. This view may also be related to cost.

The introduction of SET has been more successful in IVF clinics where treatment is subsidised. In 2003 Belgium introduced a policy of 6 free SET cycles for women under 43. The costs of treatment were 8.4 million Euros. The costs were thought to be offset completely by 9.1 million Euros saved by eliminating health care costs associated with the risks of triplets and twins (Bhattacharya and Pandian 2006). Another study has shown that a fixed charge for all fresh and frozen embryo transfers following a single oocyte retrieval led to higher acceptability rates for eSET. Maintaining existing rates of pregnancy with SET was also of importance to the participants of this study. In this study the way that information about SET was given to patients was assessed. Patients' were slightly more likely to find SET acceptable when information was face-to-face (In this study this was done by clinic staff not counsellors) rather than being given only written information (Murray *et al.* 2003). My proposition is that counselling can be instrumental for UK clinics to incorporate SET policy into the framework of existing IVF treatment protocols.

## **5.2 The Technological Construction of Desire and the individualisation of Infertility**

**The next section of the literature review examines sociological literature relevant to the social construction of IVF as a consumer product. My investigation is intended as a contribution to the sociological understandings of IVF and in particular to the practices of multiple embryo transfers and SET. This investigation views the infertile woman's desire to have children and therefore embark on infertility treatment as socially constructed. From a Foucauldian perspective, IVF technology and infertility technology have created a catalogue of discourses, disciplinary practices and contemporary understandings of infertility as a medical condition . Infertile women have become its subjects. The following section of the literature review explores the forces at play, which shape both the technology and its subjects.**

IVF has influenced the public's perception of foundational meanings connected to reproduction. The representation of traditional meanings of the family, parenting, kinship relationships, disability, morality, nature and life are altered when viewed through the lens of this technology. Women's desire to pursue IVF despite its financial, emotional and physical demands is not a natural individual response to infertility as a disease but a socially constructed response (Throsby 2004). If we are to acknowledge that a woman's motivation to conceive is a socially constructed yearning, one way to view any woman's desire to interact with the IVF process may be to accept that the choice to undertake the treatment as being not natural but as naturalised. This investigation sees the infertile woman's enthusiasm for embarking upon the procedure of IVF as a naturalised response and provides an analysis of how subjects are produced by discourse. IVF has overwhelming powers of social control as a disciplinary technology because it can incite desire and the attachment to social identity. A wealth of cultural phenomena consolidates to create and foster



a desire for this technology, the dominant one being biological parenthood. IVF upholds an emphasis on biology and this underscores traditional images of women as conceivers and bearers of children (Duster 1990). The female body is the medium through which parenthood must be obtained.

The Foucauldian process of naturalisation normalises the process of IVF as a way the infertile subject may circumvent her infertility. The IVF technology can transform discourse and experiences surrounding conception and pregnancy. Infertility itself is also of course, a socially constructed concept. IVF and other infertility treatments are the legitimised apparatus to attend to those women who have been categorised as infertile. Embarking on these revered yet largely ineffective treatments is a big sacrifice in terms of time and often commands physical and emotional costs as well as huge financial payments on the part of the individual. Such costs have again been legitimised by the processes of naturalisation and are authorised by the power of desire, which has become individualised.

In some literatures, a socially constructed human 'desire' or 'drive' to have children is explained in evolutionary terms. These instincts may provide fuel for contemporary socially constructed desires to reproduce. They are evident in argument grounded in behavioural genetics. Behavioural genetics points to humans' long history in hunting and gathering societies and argues that natural selection favours organisms who, in this particular environment, were able to have offspring and keep them alive (at least until they too reproduced). One contested perspective is that humans, like other organisms, are survival machines (Dawkins, 1976: 21) that propel successful genes into the subsequent generation. Edwards identified this 'drive' in her study of the residents of Bacup in the 1990s. The Bacup residents identified a 'biological need' to have children. However, it was acknowledged that this imperative was not absolute and was moderated and mediated by such things as careers or well-paid jobs (Edwards 2000:239).

Approximately 15% of all couples of reproductive age are involuntarily childless (Berg *et al.* 1980:58-63). The common and powerful emotional responses emphasising biological parenthood experienced by those with infertility as a medical condition, means that the individuals who are carrying this burden may put themselves in a position where they are able to accept risk to have a child. This might help to explain why women all over the world have been happy to accept more than one embryo into their uterus during an IVF cycle even though they are putting themselves and their potential children at physical risk. During her observations of patients in UK clinics, Franklin further suggests that enrolment on the path of IVF itself influences patients' emotional status during their quest for a child: "the technique can be shown to produce a greater desire for children than existed at the outset" (Franklin 1990:113). Doctors have promoted this practice of multiple embryo transfer where they are working with a technology that is largely unsuccessful and free from government regulation. Franklin and Roberts aptly explore this later in their exploration of PGD (Franklin & Roberts 2006). Here they suggest that both IVF and PGD are technologies invoke notions of hope in their consumers. However, individual hope comes into conflict with social hope for these technologies: 'Warnock argued that the one thing "everyone" could agree upon about the future of rerogenetic medicine was that it must be subject to some limits of some kind-and, at a societal level, few would disagree. Significantly, however, the same cannot be said at a personal or individual level, where the opposite principle often holds-namely that nothing is impossible, everything must be tried, no stone can be left unturned, because a moral obligation to push beyond the limits is the only guide" (Franklin 1990:209). As my investigation into patient perspectives in Chapter 8 demonstrates, there are deep differences between societies' and consumers' public recognition of limits and the determination of the individual in particular circumstances to defy boundaries.

Foucault's work on power structures and medical technology postulates that medicalisation allows power based on technical capacity rather than moral consideration. This power then becomes normalised or naturalised, encroaching on the everyday lives of the individual and eroding their status (Foucault 1980: 146-65). This perspective is summarised in US social science literature on

reproduction. It is thought that "Choice is granted as the key right of American Identity: we want the ability to choose" (Davis-Floyd 1998:6). Such an attitude is not however constrained to the US and is prominent in every consumer society. However, we need to be aware that when technological options exist it becomes less possible to choose options that don't involve these technologies. Heavily influenced by health care professionals and normative practice in a given IVF clinic, whether to accept IVF with a multiple embryo transfer or a single embryo transfer (or even natural cycle IVF) disappears as a choice. There is an inherent irony in the fact that the very technology, which proposes to increase their choices about conception, also limits them. To extend this argument further it can be asserted that engaging in the IVF process itself becomes no longer a choice but a necessity. The "existence of new technological options take away the choice simply to accept infertility" (Franklin 1998:108). Infertility becomes a tentative condition. Marilyn Strathern comments that "choice" is a consumer idiom (Strathern 1995:76-77). Such a notion of choice stands for autonomy, independence and freedom of will, signifying women's sense of themselves as having a strong influence upon the IVF process in which they are engaged. However, the way these 'choices' are formulated and presented by IVF clinicians may have a strong influence on patients' decisions (Tymstra 1989). IVF treatments may have no clearly defined finishing point and the costs of treatments may go ignored.

### 5.2.1 IVF: An individual's issue located in a cultural ideology

In spite of being individualised in the above identified discourses, female fertility and women's widespread reliance upon IVF should be understood as part of a wider social, cultural and economic social fabric. This would for example include major changes to marriage patterns in some countries that have resulted in people marrying at a later age and a rise in women's participation in the workforce. In many work environments there may be constraints related to decisions about childbearing related to maternity, feeding and afterschool care arrangements (Office for National Statistics 2007). Many other environmental factors also affect women's fertility globally. Infertility is clearly an issue for global society. However

for nearly every woman who suffers this extremely stressful condition, the burden and responsibility is placed upon the individual. The social problem of infertility has become individualised. Desires are therefore also individualised, created by technology yet leaving the burden of costs surrounding healthcare to treat this illness as a burden upon the individual.

In some countries the individualisation of infertility is more pronounced than others. However strong the impact of global processes, we should not assume that the power to define reproduction is 'uni-directional' (Ginsberg 1995:8). On the contrary: infertility and the technologies that surround them are cultural objects enmeshed in social, political and economic systems. Infertility technologies are also consumer objects than reflect their cultural context. Consumer culture is meaningful because of its ability to reproduce social identities (Slater 1994: 4-5). IVF holds the prospect of motherhood as a social identity. Technologies will derive from and be created by cultural priorities. The consumers of the technology play a central role in promoting and sustaining the technologies. In turn the technologies become naturalised through resilient dialogues and maintain the status of cultural ideologies. One way to ask how culture influences public understanding is to look at people's assumptions regarding the meaning and value they give to certain behaviour (Strathern 1997:41). Those women who are striving for the ideology presented in the technology are very liable to failure and disappointment. Failing to adhere to such a persistent and dominant ideology can bring an individual profound emotional pain and social discomfort. Cultural ideologies largely support the assumption that reproduction is central to being a person. Dialogues surrounding this give unified meaning to people's lives and are the primary means through which individuals interpret and explain reality (Clark and Anderson 1967). Women unable to biologically conceive feel different and are forced to be outside of the culturally defined lifestyle ideals that appeal to the majority of those in the culture where they call home.

In many European countries including the UK, the infertile have been slowly supported by government agency. Social support is mostly traceable over the last 10 years. In the US and Canada this has not been the case and the burden and

solution to infertility are placed entirely on the individual. This often results in "stratified reproduction" (Ginsburg 1995:3). This is where some categories of people become empowered to nurture and reproduce and others are disempowered. The burden of responsibility on the individual is also apparent in Inhorn's ethnography of Egypt (this is discussed in more detail later in this chapter), and here and in other non-western countries a further emotional individual burden may be attached to the individual who is infertile as widespread shame and scorn is attached to the condition and they may be ostracised from their community. In such countries childlessness is never presumed to be a choice.

Sociologically, the individualisation of infertility has been enforced in many countries by a neo-liberal approach to political rule, which promotes individual freedom and rights against the excessive intervention of the state (Addleson 1990). Many modern societies are organised and controlled in ways that invite voluntary participation for their citizens. The notions of freedom central to such societies reject the extent to which women's lives and their 'choices' are constrained by external social and economic contingencies. The style of government attached to a neo-liberal state may support or contribute to the lack of social infrastructure and social institutions to regulate and support the widespread fertility concerns of the public at large. The United States may be viewed as an example of this. Here the consumer culture emphasises the privacy and rights of the individual, giving primacy to issues of autonomy, choice and freedom. As a result of this a cultural imperative arises to make use of the technologies available. This cultural imperative is organised around notions of persistence and self-responsibility and control over the body. This persistence is emphasised by the biomedical science establishment and medical technology industry (Figge 1988). The medical solutions become marketed as a method of taking responsible action for one's own medical condition. This attitude of taking such action is demonstrated by those seeking solutions for a wide range of medical conditions (Sandelowski 1991). In this way this collective cultural action promotes the medical services that are sought. These ideas are reflected in Foucault's theories behind biopower (see page 142).

### 5.2.2 IVF: A Woman's Issue

The cultural narrative that all women must have children in order to be truly fulfilled and be 'real' women furthers the 'need' for IVF. The social and personal pressures to mother which are placed upon women can be great, especially when intentionally child-free women may be described as selfish, uncaring career women in a patriarchal society. Everyone's identity as a person is derived from knowledge about his or her birth and about how they were brought up. In this way reproductive knowledge and childrearing knowledge becomes social knowledge. The individual experiences a relationship with and connection to others inside and outside of their immediate family circle. Females are often socialised from an early age to be nurturing caregivers who experience self-fulfilment when tending to the needs of others. The inevitability of mothering is rarely questioned, but women who choose not to mother may find their decision frequently questioned. The assumption that all women should mother creates a convention whereby if a woman or couple is deemed to be unable to naturally have children, she or they will be encouraged to investigate and to utilise the reproductive technologies available to them to help to achieve the goal of true womanhood (Rowland, 1992:246-72). This ideology has been studied in the IVF clinic setting and it was found that women adopted the dominant motherhood discourses of the pronatalist society where they were raised and lived: motherhood, for most held a superior value (Haelyon 2006).

In the previous section it was considered how infertility might be viewed as an individual problem. Additionally, here it is considered how it may be viewed as an individual woman's problem. Despite the fact that male infertility is either the sole cause or contributing factor in more than half of all cases of infertility worldwide (Inhorn, 2003:6), it is women who are the driving forces behind IVF technology and the participants in the technology. Male infertility is rarely recognised. It has been overcome through the female participation in the IVF process with the assistance of Intra-cytoplasmic sperm injection (ISCI). We see a gendered division of labour in IVF and many other fertility treatments. This is coupled with a paradigm shift

whereby infertility treatment and its care has been driven not by diagnosis but by treatment and therefore the female becomes the site of such treatment. This medical treatment then increases women's sense of deviance from the cultural ideology of motherhood and locates the issue of infertility into the woman's body regardless of its cause. From a feminist perspective, the primary danger of transforming the female body into a site for technological intervention is that it may render the body invisible, erasing the woman while foregrounding the fetus (Ginsburg and Rapp 1995:6-7). During the often rather lengthy course of any IVF treatment the patients' image and opinion of themselves as infertile is endorsed and the patient's self-opinion will become altered because of their engagement with the treatment. This experience may be adequately explored through counselling if offered in the right way to a patient and her partner during the course of the treatment. My research demonstrates that currently in the UK many clinics only offer a minimal counselling service to satisfy licensing regulations and there is a large disparity in provision across clinics (chapter 7). For counselling discourse to offer an exploration of infertility as a medical disease and its consequences for self-identity it would as a service needed to be deeply embedded within the culture of each individual infertility clinic. Currently many clinics offer a minimal counselling service to satisfy licensing requirements (see chapter 7).

It may furthermore be considered that when women's bodies become a site for technological intervention, the process of medicalisation escalates, not only dehumanising the body, but also redirecting both patients' and clinicians' concerns away from humanistic and ethical issues toward the technology itself. This could be a contributing factor for the widespread acceptance of multiple embryo transfer. Patients may become drawn onto the clinical steps of the process and in doing so their concerns surrounding the technology may become muted by their engagement in it. Once a patient has made the first choice to enter the IVF clinic and engage with the technology in it the pace of the technological steps can take momentum and any opportunity to make further choices pertaining to the technology itself may not be apparent. The provision of counselling as a forum for the discussion of such concerns can allow such patients to pause for reflection.

IVF helps to ensure that men and women can have children that are genetically related to them. It is often assumed that it is the women's desire for children that is the driving force behind this technology. However a study conducted by Crowe in the UK, focusing on women's motivations for participating in IVF programs, found that women did not place primary importance on the biological or genetic link to children, but that 'social motherhood' was more important to them than the transference of genetic traits involved in biological motherhood (Crowe 1987:87-88). However for men the opposite applied. The men placed the genetic relationship to children as the most important relationship and several women stated that their husbands would prefer to have no children than to adopt children (Crowe, 1987:87-88). Therefore one reason women enter into IVF is to allow their husbands the opportunity for a genetically linked child. We cannot generalise Crowe's findings to all women in IVF, but she does draw our attention to the fact that it is not only women that may desire children, but men often desire genetically related children. Lasker and Borg concluded that, since men 'cannot carry, birth, or nurse a baby' nor are they the 'major care-givers,' many men believe that their largest contribution to creating a child is through contributing their genes or genetic material (Borg 1998).

Throsby's research gives a clear outline of the gender divisions of labour during the IVF cycle. She clarifies the IVF process itself and draws attention to the fact that it is wholly performed upon the woman's body. Epidemiological statistics suggest that the male partner is implicated in 50 percent of infertility cases worldwide. Yet it is the women who take most of the drugs and undergo most of the ultrasounds, hysterosalpingograms, surgery, and other invasive procedures (Cussins 1996). The centrality of the woman's body and the woman's labour that is intrinsic to IVF treatment is often invisible from popular discourses surrounding IVF. The women Throsby interviewed all organised the drug treatments for IVF themselves with limited help from their partners. They were the ones who took time off for lengthy appointments and invasive medical procedures. They collected prescriptions and either injected themselves or found other people to do so when partners were



unable/unwilling. It is Throsby's finding that this gender division of labour during the IVF cycle transfers the responsibility for treatment outcome from the treatment providers to the women themselves (Throsby 2002:72). This is pernicious because it has the effect of being potentially disruptive to any attempts of achieving closure around the experience of IVF and move on to either childlessness or other forms of parenting.

Throsby's interviews were conducted in 2000 and the culture of patient support has changed somewhat in some clinics in the UK. This has mostly been the result of the statutory introduction of counselling services in the clinic. However, her ideas about the transfer of responsibility that occur during various technical procedures in clearly identified stages of the IVF cycle are relevant to my investigation into UK clinic support services because practical support services in relation to administration of drugs can easily be improved within the culture of the clinic. These support services can also encourage partner participation. It appears that partner participation in the IVF process needs promotion and active encouragement. Actively engaging in all levels of treatment is unlikely to be inherent in many male's responses and attitudes towards treatment. In other research Throsby investigates male experiences of IVF and its intersection with masculinity (Throsby and Gill 2004). Throsby uses the concept of 'hegemonic masculinity' (Connell 1995). This type of normative masculine standard is defined by repudiation of the feminine other. In the IVF clinic Throsby discovers 'an emotional script of masculinity, which not only left many of the women feeling that they were going through the emotional aspects of the experience alone but also left the men isolated and without any source of support' (Throsby 2004:160). Masking emotions may be an expression of profound distress as they try to meet the cultural expectations for manhood by being controlled and impassive.

### 5.2.3 IVF: A Global Issue

IVF as a medicalised consumer product is a product of social change and a conduit for social change. As a social phenomenon IVF is complex to study because the social changes surrounding it are happening on a global basis. The historical

vehicles for such changes are processes of industrialisation and consumption. These have shifted over time from mass production to flexible accumulation. The use of IVF is an example of this shift (Clarke 1995:149). Some Middle Eastern ethnographies I read demonstrated some of the complexities behind the global provision of IVF. This literature was readily available to me in my search to locate IVF within the context of cultural ideologies surrounding pregnancy, motherhood and parenthood.

Marcia Inhorn's extended ethnographical analysis situates IVF practice in Egypt, in the global debate about tensions between locality and globalism in the realm of science, technology and medicine. Her work focuses upon global and local forces and their intersection with gender, religion and in vitro fertilisation. The work was useful to my investigation of support services because the interviews with the largely Muslim women in her work made clear that such patients were not willing to utilise support services and in fact found them to be positively distasteful. IVF patients generally desire privacy, even total secrecy when pursuing IVF treatments due to cultural issues of stigmatisation that exists with regards to both male and female infertility. In Egypt the severe moral stigma associated with IVF militates against the formation of local support groups or indeed of any hint of IVF seeking or experience to others in their social worlds: "Here, support groups are not going to work. It needs people to be frank. When one of us has financial problems and a doctor asks us, we will be truthful, but not when we're sitting around with other people. We believe that if you talk more, you have more problems" (Inhorn 2003: xiii). Inhorn's ethnography suggests that not all patients will respond to support, particularly in the form of counselling and support groups. Other stress reducing non-discursive types of support may be of value to such patients during the IVF cycle. Most clinics in the UK provide treatment information in a variety of languages and translators are available. This suggests a multi-cultural clientele and support services should be diverse to have wide appeal.

Like Egypt, certain facets of Israeli social life may be seen to display some elements of fundamentalist pronatalism. Both countries exhibit a pro-natalist culture and "pro-family" value system that is contextualised within religious and to a

certain extent state culture. However, unlike Egypt where IVF exists as privatised medicine, in Israel IVF services may be seen to be endorsed by the Jewish state in the form of widespread free infertility support. Israeli society has the highest rates of artificial reproductive technology (ART) intervention in the world, as well as the highest per capita rate of infertility therapy, with IVF at its centre. Few restrictions exist for individuals to utilise free fertility treatments (Gooldin and Shalev 2006). Israel's global position in relation to IVF provision is unique and useful to my analysis of UK IVF support services. In Israel the support offered to patients is practical and financial in terms of cost and availability of services. This may be politically driven and embedded in the state's somewhat muted interest in enlarging its Jewish population (Birnebaum- Carmeli 2004:107). There are also interesting processes at play within the institution of the Israeli IVF clinic and these processes arise largely from the fact that Israel does not subscribe to the American model of the separation of religion from the state. Kahn's ethnography about Jewish experiences of IVF explains how rabbinic law and state law have together constructed IVF protocols, regulations and management systems in the IVF clinic (Kahn 2000). From a sociological perspective it may be observed that Israel is unique in that a level of patient support in the form of religiosity exists in the very framework of the clinic itself. Outside of the clinic many religious charities offer free advice and support for couples suffering from infertility. The Israeli government's IVF policy is not without its critics in its management of economically limited health funding (Gooldin and Shalev 2006). However, it demonstrates how a society has been able to relocate the social problem of infertility from a private to a public sphere.

Although slower to do so, in recent years the UK has also started to change infertility provision, bringing it into the public sphere by providing limited free provision for certain individuals. My investigation analyses public policy pertaining to IVF, by investigating support services in IVF clinics. Such support services, for example, counselling services and patient support groups attached to the clinic, encourage the patient to seek help outside of the more traditional models of individual self- support, administered solely by the IVF recipients themselves or maybe accompanied by any support offered by their immediate social circles.

Provision of adequate patient support could serve to both empower the patient and lessen individual responsibility for their infertility. Through mechanisms of support the social problem of infertility becomes less individualised.

#### 5.2.4 Cussins: Processes of naturalisation in the IVF clinic

Cussins spent many years studying IVF clinics in the US. Reading her research, it is evident that she wishes to make clear sociologically that clinics do not merely approach their patient's infertility through the application of medical knowledge. Her investigation of certain US clinics suggests that the culture of multiple embryo transfer has become "naturalised, normalised and routinised." These are interconnected processes within what she labels the "Socio-natural" world of the IVF clinic (Cussins 1996:83). There are forces, which play a part in creating the internal environment of the clinic through their interconnection with social lives, material reality and expertise. Cussins adopts the Foucauldian concept of Naturalisation for the IVF clinic setting and suggests that new data for the clinic are incorporated into systems already in place and reproduced and changed over time. These concepts are interesting and dynamic tools to view the culture of the infertility clinic. My investigation into the two topics of patient support and into single embryo transfer can both be viewed through the lenses of these concepts.

Naturalisation is where certain practices become self-evident. In the case of the institution of the IVF clinic we can observe that new data for the IVF clinic are incorporated into systems already in place and reproduced and changed over time. In this way new techniques evolving through constant scientific advances become absorbed in clinic practices as naturalised constructions. A good example of this is ISCI, a technique to allow less mobile sperm to penetrate and egg by direct injection. In many clinics I visited in Canada ISCI was routinely offered to all patients at an increased cost and sold as a method to increase success. Research evidence has indicated evidence of a variable rate of success when using ICSI unrelated to any diagnosis of male fertility problems (Svalander 1996; Maiburg *et al.* 2009)). Later research has shown that this injection may be detrimental to

those with sperm that can penetrate an egg normally as sperm that may be less than healthy are artificially encouraged to achieve conception (Davies 2012). However, ISCI has become a naturalised technique and patients (including myself) agree to buy it as it adds fuel to our notions of hopes and desires that surround our ability to access the technology of IVF itself. There is no reason why SET cannot become a naturalised part of IVF practice in the same fashion. My investigation identifies issues surrounding resistance to its naturalisation at a clinic level and proposes the promotion of discourse within the clinic to explore motivations behind patient contentions. Routinisation is local knowledge used in conjunction with technologies. An example of their inter-related nature can be described in the use of ultrasound, which is a routinised skill that will determine both the normal and the natural.

Adequate patient support or sufficient attention to multiple pregnancies are both concepts that are arguably as yet not integrated or normalised into the structure of IVF clinics. In the UK both of these are subject to policy regulation by the HFEA, however my research in chapter seven demonstrates that implementation is variable across the country. With regard to patient support, it can be argued that certain behaviours to be expected from IVF patients have been normalised. My experience of IVF clinics has demonstrated that lapses of control or any outward indication of failure to cope by patients are not encouraged. Control in the couple is a model for the baby-centred heterosexual nuclear family that is normative for the society that the clinic markets itself to. Any lapse of control on the part of either patient demonstrates to their clinic unsuitability for parenthood. Cussins observes that 'At all points a couple undergoing treatment must behave appropriately or they risk forfeiting their status as patients' (Cussins 1996:73). These standards of behaviour promote a highly compartmentalised arena for patient support services. Cussins' visits to clinics in the US also noted that the containment of stress is promoted (Cussins 1996:156). Although the gendered stress that is both psychophysical as a result of hormone treatment and inherent in the procedure itself due to its intensely stressful nature, is acknowledged by clinic staff it must be contained and managed within the confines of a counselling room. Cussins felt that the clinic expected a certain manner of behaviour from patients because the

baby-centred, heterosexual nuclear family was normative for the society in which the clinics are positioned (Cussins 1996). Stress as a result of treatment is both gendered and contained so that a couple may display their suitability for treatment and a clinic may justify dispensing with such treatment.

In the UK counselling has become somewhat integrated and normalised by some clinics in the United Kingdom although currently there is a huge disparity in provision across the country (see chapter 7). If counselling provision were expanded and all patients encouraged to visit the counsellor then it is possible that the counselling room may be a forum to encourage patient discourse and air concerns relating to the procedure. Studies suggest that patients find their experience of counselling to be positive regardless of whether it is voluntary (Stewart *et al.* 1992) or mandatory (Connolly *et al.* 1993). These studies suggest that mandatory counselling could be well received in the IVF clinic setting prior to embarking on treatment. As a sociocultural construction counselling is a useful tool for clinics because it serves to remove some patient issues surrounding the IVF process itself that may interfere with the clinical medical procedures. This may include any patient's resistance to SET. Clear and detailed information relating to SET can be imparted to any patient before embarking upon the procedure and questions and discussion about the procedure promoted. The clinician will then be able to assess the patient's suitability for a treatment that will be free from misconceptions and with full and informed consent.

Like patient support, attention to the promotion of SET and the subsequent avoidance of multiple pregnancies are practices that remain unintegrated into many IVF clinical settings. One way of increasing single pregnancies would be by promoting natural embryo transfer whereby the patient's own single eggs are extracted, fertilised and replaced. The transfer of one embryo does not alter the likelihood of a singleton pregnancy or birth when compared to the transfer of two or more embryos (Dare *et al.* 2004:284). Natural embryo transfer is cheaper and increases patient autonomy whilst eliminating all of the negative effects of superovulation. Natural embryo transfer can also be used to harvest donor eggs.

In non-donor IVF cycles, super ovulation may not just affect patients' general health but also their ability to sustain a pregnancy after embryo transfer. IVF doctors currently do not promote the practice of natural cycles because they are not integrated into the structure of the clinic. During her observations at an IVF clinic, Cussins observed that patients choosing natural cycles were discouraged because of the risk of losing just one egg during or around the retrieval process (Cussins 1996). This one disadvantage overrode the many disadvantages of super ovulation because such practices had not been integrated into the clinics she observed. Cussins argued that for natural cycle IVF to be an accepted procedure it would have to be successfully incorporated into practice and this would mean generating a liveable dynamic for both patients and practitioners (Cussins 1996). On a clinic level this requires a careful and thorough integration into the evaluative structure of the clinic and not a simple grafting onto existing protocols. Currently, despite the benefits of such procedures they have little chance of uptake when lying outside of the difficult to penetrate boundaries of what Cussins terms naturalisation, normalisation and routinisation of clinic procedures. Here there are some similarities with patients' perception of and take up of SET.

Cussins views the IVF clinic as an intriguing and dynamic cultural site in which to make sociological observations. Her observations are useful as a backdrop to my investigation of the implementation of policy because they promote the legal implementation of regulation in the clinic as a way to break through the barriers of normalisation, naturalisation and routinisation. Such processes acting in the environment of the IVF clinic as an institution are rigid and powerful and impenetrable to patients. Effective public policy can promote an equitable application of medical treatment that transcends such barriers.

#### 5.2.5 Throsby and Franklin: Patient experience

Throsby is very attentive to the concept of naturalisation that is inherent in the technology of IVF and the status that the technology has been granted in modern society. She has argued that the dominant cultural representation of IVF locates it centrally within modernity in 'a seductive image of benign, rational, efficient science

giving imperfect nature a helping hand' (Throsby 2004:2). This was reflected in the marketing of the IVF clinics that I visited in Toronto and in the on-line and documentation marketing material that I looked at from IVF clinics in the UK. A prospective patient may have no idea about the invasive nature of the technology on the body, long waits in the clinic, repeated failure of the technology and the complications surrounding potential multiple births. Indeed in the clinic where I eventually used the IVF technology, I found the waiting room to be covered with pictures of multiple sets of newborns accompanied by the smiling clinician. The naturalisation or normalisation of IVF is intensified by its prolific appearance in and often saturation of popular discourse. The culturally dominant representations of IVF have become mainstream and unproblematic. Throsby is of the opinion that this tends to 'alleviate the perceptions of risk which might previously have functioned as a reason not to have treatment' (Throsby 1994:39).

Throughout her work 'When IVF Fails', Throsby points to the resonance between cosmetic surgery and IVF. She does this because both technologies involve the 'modification and management of the body' (Throsby 1994:5). She believed that post treatment the patient's body is modified and pays attention to the rather common outcome, that of failure rather than the outcome that accompanies the public image of IVF. Cosmetic surgery has also become naturalised as a technology in a very similar fashion to IVF. It is also marketed as benign, helpful and efficient as an answer to overcome the 'imperfections' of the body associated with the aging process. Like IVF it has become increasingly prolific in popular discourse. Both technologies are susceptible to 'technological creep' (Throsby 1994:192). This is where existing technologies become normalised in comparison to newly controversial technologies.

Both IVF and cosmetic surgery often presume a white middle-class subject. I studied on-line and document literature from the one IVF clinic in Exeter and the two cosmetic surgery clinics and all literature confirmed this. This may be related to the socioeconomic stratification of both consumer products based on their cost, which can be racially profiled. They are both class based phenomena and the extent to which class is linked to ethnicity in the context they are marketed will



influence access to some individuals (Nsiah-Jefferson and Hall 1989). However sometimes other discourses surrounding this stratification are present. Ceballo highlights this in her account of the experience of infertility of two black women (Ceballo 1999); she found racist assumptions of hyper-fertility in black women rendering their fertility as easily disregardable, causing one woman to describe herself ironically as “the only black woman walking the face of the earth who cannot have a baby”. IVF is a technology that puts many people in debt in order to attempt to have children and leaves others out completely. Despite these technologies being contingent on class and race and carrying detriment to a patient’s emotional and physical health, they are welcomed by society and consumers as a ‘helping hand’ and have become naturalised as normative social constructions in modern societies. In the case of IVF as portrayed as nature’s ‘helping hand’ that appears to promote family values, ironically the reverse may also be true as it may fragment and dismantle conventional family categories. IVF can enable the creation of new types of family structure with new legal and social definitions.

Together, IVF and cosmetic surgery technologies create a category of users that feel that it may be difficult to choose not to engage in the technology. By refusing to engage they are defying social norms and either ‘not trying hard enough’ (the case with IVF) or ‘not making the best of themselves’ (the case with cosmetic surgery). They may feel or they may feel perceived by others as unnatural or abnormal. Both technologies are prolific in the UK. They are very expensive; carry side effects and failure rates. For the users of IVF technology it is also hard for a patient to decide when to disengage with the technology. Throsby describes this experience, as ‘being on a treadmill from which there is no apparent exit point’ (Throsby 1994:8). This is because the cyclical nature of IVF provides a seductive ‘maybe next time’ promise. The patient becomes enticed to gamble again. The lack of alternative ways to gain the child that is desired and the ‘epistemic culture based on statistics’ (Cussins 1996:75) contribute to the culture of perseverance in the gamble to conceive. In the course of Cussin’s research she found that when success projections were based on statistics, cumulative probabilities made it easy to supersede any treatment guidelines (Cussins 1996). However she also noted

that statistical projections meant that all cycles must be relatively the same and they never were which also lent itself to 'another role of the dice'. The whole infrastructure of the clinic operates and validates itself upon the existence of these rather fragile statistics. The 'success' of IVF procedures generates the statistics and then the statistics justify carrying out the IVF procedure. Cussins points to the fact that without the statistical justificatory system working, all the other repertoires of normalisation and making things relevantly the same cannot be calibrated and validated (Cussins 1996).

These same statistics demonstrate evidence that relatively few women, after enduring the physically, emotionally and damaging effects of IVF, actually achieve motherhood. Participation in treatment is demanding, time-consuming and disruptive to work and other life activities. Treatment failures are often a source of deep disappointment, sadness and depression. Language is a very powerful tool. One could speculate that if the term 'failure rate' was utilised, there is the possibility that fewer women would subject themselves to treatment. The term 'success rate' offers hope and an optimistic outcome to the men and women involved in IVF. In order for scientists, doctors, and clinics to continue their research, generate profits and prestige, and to ensure that a steady supply of women enter into IVF programs success rates must be quoted and even sometimes manipulated. In the early 1990s, American, Dr. Soules in an editorial in the journal *Fertility and Sterility* called the statistical manipulations a 'marketing ploy' to help ensure an adequate number of patients for the maintenance of IVF programs (quoted in Rowland, 1992:45). He goes on to say that rates given for 'success' demonstrate that approximately 80% of women that undergo IVF will not have a baby after the procedures are over. He felt that with a failure rate of this magnitude IVF was clearly an experimental technology carried out upon and inside the bodies of women. In more recent years pregnancy rates have improved. HFEA data showed that in 2008 the national average rates for 'Live births per treatment cycle' were: 32.2% in women under 35, 27.7% in women 35-37, 20.8% in women 38-39, 13.6% in women 40-42, 5.0% in women 43-44 and 1.9% in women over 44 years of age (HFEA 2010). However, failure of the technique is still high, particularly in women over 35 years old.

In the course of her research, Franklin investigates IVF failure. In the IVF clinics she found that women expressed two primary aims in relation to IVF: if they succeeded they would achieve the ultimate goal of a take-home baby, and if they failed, at least they would know that in theory, had tried everything (Franklin 1990). However 'the if-not-a-baby-at-least-peace-of-mind logic occasioning the initial decision to opt for IVF is discovered to be ore elusive than anticipated' (Throsby 1999: 112). For patients who had yet to undergo the arduous cycles of IVF, these alternate resolutions were seen to guarantee success: one way or another a positive outcome was assured. Franklin followed patients through treatment cycles in an attempt to understand them as a social dimension of a changing conception narrative. What she found was, that IVF failure was an elusive concept (Franklin 1999). There was no obvious point of completion of treatment and this was especially apparent in the large proportions of patients where infertility was unexplained. The decision to engage in IVF then at the outset which hoped to offer a vehicle for gaining certainty and autonomy over a given patients infertility only offered these patients more uncertainty. Franklin explains that 'far from settling these unresolved issues about the future, IVF often renders them *more* tentative. As it becomes increasingly clear that there are always new options to be tried, always more ways to increase the chances of success, the possibility of finding resolution becomes more remote' (Franklin 1999:111). This perspective of IVF failure and the implications for the individual is important and should be a part of implications counselling that IVF clinics offer prior to engagement in programs.

Much of Throsby's research also concerns women who have faced IVF failure. Even with today's improved success rates there are masses of women in the UK that fall into this category. She pays special attention to the invisibility of failure both in the clinic and in wider society. For Throsby, concentrating on failure can 'offer valuable insights into the wider social and cultural context within which IVF is produced and maintained' (Throsby 1994:9). This is important to my investigation, as failure is a strong rationale for analysing engagement with counselling and support. Failure is a key issue for support measures in IVF clinics and particularly concerns therapeutic counselling. During her research, which specifically analyses

discourses of health and illness in accounts of IVF failure, Throsby explains that women experiencing IVF failure construct themselves as "both healthy and ill" to establish normality and legitimacy in their engagement with IVF services (Throsby 2003:64). These women are often caught between these two discourses concurrently but temporarily located in both. This is both a troubling and unsettled position for the female involved and linked to the association of normality with motherhood. The categories themselves are fluid normative discourses reflecting social and cultural ideas about technology, gender, reproduction and the female body.

#### 5.2.6 IVF: transformation and opportunity for self-agency

Throsby believes that striving for these norms as an outsider helps to put the women in a position of resistance to them. Throsby believes that 'Women engaging with IVF are never entirely without power, although they will always be individually located more or less favourably to it' (Throsby 1994:43). Depending upon their location in their infertility and subsequent IVF journey it could be that 'spaces between the stories' (Braidotti: 1994) can give potential for the transformation of the IVF patient. Therapeutic counselling in the clinic may be a forum for the IVF recipient to discuss the function of these types of social relationships and how they exist in their own feelings about their condition. Throsby portrays IVF in a fashion that allows an analysis of all the power relationships at play during IVF. She views IVF as a form of 'material-discursive action' (Throsby 1994:47). Throsby identifies women as users of the IVF technology rather than a recipient or victim of them. In this way an IVF patient is able to understand their position in relation to their infertility by using all the resources available to them. Throsby's work points to the usefulness of thinking about IVF as a technology through which new identities and norms are produced through the negotiation of many power relationships. This was instrumental to my decision to examine IVF and IVF counselling as an examination of relations of biopower and led to an inquiry that implied the work of Foucault, incorporating some of his ideas about biopower.

What Franklin also acknowledges is that a woman's interaction with the IVF process, despite of its failure rates and its addictive nature can be transformative. This is because she feels that interaction with the technology can produce new ways of understanding and thinking about relatedness (Franklin 1999). Again the intersection of a promotion of patient 'voice' in the form of counselling opportunities may maximize any patient opportunity to expand their transformative understandings. Through counselling an IVF patient may be able to begin to learn to exert agency over her body and over the IVF process itself. This can involve decisions regarding clinical procedures such as SET. It may also involve an interpretation of infertility outside of a medical context. Following IVF treatment those engaged in it will need to redefine their relationship with notions of biological parenthood. As a culturally dominant ideology this redefinition may include not only the IVF patient's partner but also extended family such as intended grandparents. A grieving process for unborn children may be involved. However evidence suggests that the cultural ideology of the family holds greater power than the cultural ideology of the biological child (Modell 1994). Therefore in the later stages of the IVF experience these alternatives may be explored with the help of a trained infertility counsellor.

### **5.3 Biopower and IVF**

**My investigation examines IVF through Foucauldian lenses with the intention of analysing how some Foucauldian interpretations are useful in exploration of counselling as a unique patient service within the institution of the infertility clinic. I have decided to situate my study within a Foucauldian perspective because Foucault uses language and discourse as a key variable in explaining how social power is exercised. I believe that language and discourse do dictate the authority in the institution of the fertility clinic. This largely lies with the clinicians and other staff in the realm of technical language relating to procedure. My hope is that some power shifts may be possible if dialogue is able to be transferred to the IVF patient: My**

**proposition being that the counselling and support services attached to IVF clinics in the UK are an appropriate forum for this.**

Foucault offers us conceptual tools for understanding the body from a sociological perspective. His work has been extremely influential on the sociology of the body and of health and illness. In the early 1990s, Turner suggested that the number of recent publications on the body 'are a testimony to the profound impact of Michel Foucault on modern developments in medical history and medical sociology' (Turner 1991:272). Foucault's work on the disciplined society provides an analysis of the connectedness of the body, self and society, thus combining the macro and micro traditions of sociological analysis (Silverman 1985). Foucault uses language and discourse as a key variable in explaining how social power is exercised. In the case of the fertility clinic, the reproductive self becomes created within narratives of reproductive technology. For Foucault, language and discourse circumscribe social reality. The current language and discourse surrounding infertility and the body are cultural entities located in a specific context. However, Foucault is unique in this tradition in that he insists that historical processes gain insights into present social processes. For example, current language and discourse surrounding infertility can be located during historical processes surrounding the ease of women's access into the labour market.

According to Foucault's theory of Biopower, the emergence of government concern with regard to the health and physical well-being of the population in general, is one of the central objectives of political power. An assumption of this thesis is that, in modern society, the human body is a political tool. The human body is perpetually subject to scrutiny through the provision of comprehensive health care availability. This is supported and reflected in the social media and often supported in public education provision. Consequently, the knowledge of our bodies, contributes to the development of social policies that in turn are aimed at the alteration of bodies. The emergence of government concern with the human body can be traced back as far as the 18th century. The context for the development of biopower arose essentially out of a change in the way the state worked. There was a movement away from the state being a superior and supreme entity. Its

people became resources for the wealth, strength and power of the state. Since the classical age, the West has undergone a very profound transformation of mechanisms of power overseen by the state (Rabinow 1984:259). In ancient times the sovereign exercised rights over life only by exercising the right to kill, or to refrain from killing. In current times it is almost as if we see a reverse in the rights of the state. The focus is upon ensuring, maintaining and developing the life of the social body. Wars are waged on behalf of the existence of everyone in a state, no longer in the name of a sovereign who must be defended. During the classical period 'the old power of death that symbolised sovereign power was now carefully supplanted by the administration of bodies and the calculated administration of life' (Rabinow 1984:262). These new procedures of power that were devised during the classical age and employed through the eighteenth and nineteenth centuries were what caused our societies to go from 'symbolics of blood to an analytics of sexuality' (Rabinow 1984:269). The shift in power moved from war and famine to norms, life, and regulations. Foucault describes this as a transition from sanguinity to sexuality (Foucault 1978:59).

In the late eighteenth century and into the nineteenth century a significant consequence of biopower was its influence on the legal system. Legal power was now taking charge of life and so needed 'continuous regulatory and corrective mechanisms' (Rabinow 1984:266). The sword became less dominating in terms of the power it possessed and the law operates more and more as a normal and effective channel of power. The judicial institution is increasingly incorporated into a continuum of apparatuses whose functions are for the most part regulatory. Alongside this came the development of eighteenth century medicine. This emerged out of 'the consideration of disease as a political and economic problem for social collectivities' (Rabinow 1984:274). Medical assistance was provided as a matter of political policy and doctors and medical knowledge become sites of social power.

Foucault saw this change in state apparatuses and the power they exercised and perceived what he termed 'biopower' to be an indispensable element to the

development of capitalism. Foucault saw the physical body, as a resource to meet the interests of the state, and therefore a proper and significant role of the state is population management. Biological life, for Foucault, is a political event. Population reproduction and disease are central to economic processes and are therefore subject to control. Foucault saw that productive populations need regulations and legal frameworks. Bio-politics is the pole of bio-power that employs regulatory controls and interventions to manage the population (Foucault 1978:139). Economically, such mechanisms are more efficient in terms of state management when there is an emphasis on self-surveillance and a role for the mother and family in promoting this. The power wielded through the medical system also operated on the economics of self-surveillance and obligations were imposed on parents to ensure development into adulthood. Foucault viewed the family as “the first and most important instance for the medicalisation of individuals”. The family is assigned a linking role between the general objectives regarding the good health of the social body and the individuals’ desire or need for care (Foucault 1980:174). Health policy can be defined as the visible power structure to handle the collective processes concerned with the life and health of the population. Whereas self-surveillance in the form of self- health care and preventative medicine, for example the taking of vitamins at home, can be defined as an invisible power structure. These practices are examples of and the expansion of the domain the health system into private life. Foucault thought that biopower largely concerned technologies that developed from the human sciences and are ‘used for analysing, controlling, regulating and defining the human body and its behaviour’ (Danaher 2000:64). Foucault analyses and defines the relationships that occur between the human body and institutions of power.

For Foucault, power becomes based on political rationality, which promotes the health and welfare of the individual and ensures the welfare of the whole. This rationale invokes a moral code and distributes techniques of power through knowledge and social practice. This encourages the production of knowledges (from natural and social sciences as well as popular culture) that allow the state to scientifically analyse the population and subsequently through such knowledge the state can therefore introduce policies, which regulate our behaviour for the good of



the individual and therefore the state. Knowledge and truth are produced out of a power struggle between different fields, disciplines and institutions and they are used to authorise and legitimise the workings of power. Their paramount objective is to keep the population happy and healthy and therefore productive. The way people understand the world, behave, their values, aspirations and the way they respond to events are fashioned out of the various apparatuses and technologies of biopower. Such a dominating force works on everybody regardless of social position. It defines each individual as in this way it is an effective social control without prohibiting actions of individuals said to be autonomous. The type of power Foucault envisages is fluid and omnipresent. Because he sees power as mobile and contingent, it moves around and no one owns it. For Foucault, power functions through ever-changing relationships between groups and institutions within the state.

Foucault saw such techniques of power to be productive. Power is not primarily repressive but has positive effects. Foucault sees power as a net-like organisation that circulates as a positive network of relations. Power does not prevent discourse; it produces it (Foucault 1984:61). Relationships of power operate on the body to “transform it, divide it, invest it with capabilities and train it to perform certain functions”(Foucault 1979:25). The body is the site of self-transformation. The individual subject is produced through this operation of power in two senses. He or she is subjected to the actions of others where the body is the object of disciplinary power and he or she gains a social identity through self-knowledge where the body is the object of self-reflection and the subject of confession (Foucault 1980:212). Disciplinary power works not by force or violence, but through the creation of new norms. Normalisation is the creation of new objects and subjects of knowledge. The political space that health care and policy constitute is an important site for the exercise of disciplinary power. In this way health policy can be viewed as a form of policing specifically concerned with the quality of the labour force as it exerts control over individuals and populations. Health professionals are entitled by virtue of their scientific knowledge or power to promote health care. However such power exerted is productive and stimulates knowledge and discourse, as power and knowledge according to Foucault were

never separate. When one increased there was a corresponding increase in the other, considered by other theorists such as Marx and Weber to be its nemesis.

We can see therefore that through the notion of biopower the body becomes the site of the guiding beliefs and ideals of the nation. It is therefore of paramount concern to the state to consider "What mode of investment of the body is necessary and adequate for the functioning of a capitalist society such as ours?...One needs to study what kind of body the current society needs" (Foucault 1980:58). Foucault suggests that bodies are made to fit within a given social structure. In this way the moral code doesn't govern the self but constitutes it. The thesis that runs through Foucault's work for the most part is that we are subjected, dominated and controlled via the very social discourses and practices that purport to guarantee our freedom. This is because knowledge and power are complex and unknowable to us in their true sense and involve agencies and institutions beyond the authority of the state. Discourse is a surface manifestation of knowledge and power but cannot be reduced to texts because it is disseminated into the very fabric of social structure. Medicalisation is an example of such discourse evident in society. Sociologically speaking, everyone lives under the regime of medicalisation. Warnings about health risks occur everywhere and we are constantly throughout our day urged to conduct ourselves in ways to avoid potential disease or early death.

We can argue from Foucault that the maternal body comes with a very unique social significance. It is the site of the reproduction of the social body. If the inhabitations, disciplines and normalities of our bodies which are destined to become part of the community or social body begins before or at birth, it follows that there would be a large state investment in the monitoring of reproductive and childcare practices. Even with a normal pregnancy what a mother does with her body is a 'legitimate' target for moral concern. State regulation is concerned with what she ingests and how she moves and when. Surveillance occurs in the community also because of concern over public investment in the social body. I myself discovered this when ordering a coffee in North America when pregnant. The assistant informed me that caffeine was considered unhealthy for the unborn

child and I was socially coerced into buying a decaffeinated drink. This attitude can also be observed in regard to social behaviour regarding smoking and drinking of alcohol whilst pregnant. Government policy exists to ensure that both tobacco and alcohol are sufficiently labelled to warn pregnant women of health consequences.

Foucault's theory is one that can be deemed appropriate as a backdrop to my investigation into the state interest in UK reproductive health policy. IVF clearly fits the model of disciplinary power. IVF involves sophisticated techniques of surveillance and examination of patients that make them new objects and subjects of medical, legal and state intervention. Reacting to desire and affirming the attachment of individuals to specific identities creates new norms of motherhood. Although in the context of Foucault's theory IVF is positive because it enables those who may otherwise be unable to have children to contribute to the health of the future workforce, IVF can be viewed as a productive and humanitarian 'power'. However, IVF as a new method of human procreation also comes with complications that affect both IVF patients and wider society as a whole.

Reproductive technology has especially had an impact on the form of the nuclear family unit where donor gametes are involved. The evolving shape of the nuclear family often carries with it uncertainty and misunderstanding. Although IVF is now considered to be a routine procedure, those instances where its use is seen to challenge dominant social norms and conventions generates social debate. There is a dialect between IVF (using donor gametes) and issues of kinship and identities, which in turn are imbued by morals, values and ethics. Society has seen a growing interest and concern with the topic of human identity that has been brought about by legal and social changes, which have had to occur as a result of technical transformations in human reproductive medicine. It is clear that IVF has destabilised conceptions of motherhood and in itself offered alternative sites of power by identifying and legitimating alternative forms of motherhood through the use of its technology.

The widespread adoption of IVF can result in the risk of multiple births, which

compromise the health of mother and baby and result in health care costs. The problem of multiple births arising from aggressive techniques pertaining to IVF may be associated with the notion that infertility is currently in our social world highly individualised. When this illness is taken out of the public domain desires may be constructed surrounding the industry associated with the treatment. Reproductive technology produces consumers with expectations and desires. Such desires have in a sense created the problem of multiple embryo transfer both to fulfil the desires of the individual and to perpetuate the effectiveness of the industry. In the UK there is a tension between the very limited state provision of reproductive assistance and the need to decrease multiple births as a public policy issue. Limited health care provision individualises the illness of infertility. Multiple births become a product of the individualisation of this illness. We observe a contradiction between state policy and provision. This research proposes that counselling associated with the fertility clinic is a potential way of, or site for, resolving this tension. This investigation proposes that counselling is a forum within the clinic to reduce the pressure that is exerted upon the individual both as a consequence of their medical condition and as a result of their engagement in the treatment process itself. Treatment options may be clarified and discussed. At its best counselling should be neutral from the interests of the industry. The institution of the infertility clinic operates to control the emotional response of the patient. Counselling is a space for expression and engages the patient as a subject.

Public health policy in the UK, has so far sought to address some issues surrounding infertility by a) setting limits on embryo transfer numbers and b) assuring that gamete donors and recipients have access to counselling that allows them to discover and creates awareness of the full implications of their decisions. Staged limits concerning numbers involved in IVF transfers are being given to UK clinics through policy created by the HFEA. Decreasing the multiple birth rate in UK clinics will occur over several years and is an illustration of what Foucault terms 'governmentality' (Foucault 1991). This is governing at a distance with a mixture of self and external surveillance. The clinics are encouraged to perceive the multiple births phenomenon, as a universal one and each clinic is required to adopt a plan and accept responsibility for transforming their own practice at an individual clinic

level. The use of counselling in the clinic promotes Foucault's assumption of the enabling role of language. His suggestion is that through language we can learn other ways of thinking and feeling. Examining the self, through counselling and other forms of verbalisation has become commonplace and increasingly accepted in British society. However, to be effective, counselling needs to promote discourse on a broad basis outside the main narrative of the fertility clinic. That is, outside the subjectivity of the medical domain. In this way counselling may offer a patient a window to view how narratives influence thinking and offer a potential site for any necessary resistance to treatment.

Foucault shows, through the example of the attitude of liberation, how power always creates its own 'other' and its own opposite (Danaher 2000:95). In this way the power created through IVF that is enabling and humanitarian can be criticised. IVF has not met with unbridled enthusiasm. Patients are required to take large doses of sex hormones, which can have dangerous side-effects. It is still a largely ineffective treatment with a success rate of less than 50%. It is expensive and available to only a small sector of the world's infertile, mostly thin white, western middle –class women. Also it does not determine the cause of the individual's fertility. The female is not treated holistically in an attempt to discover her individual reason for not conceiving. Important alternatives may be glossed over when a technological fix is presented. Instead, IVF circumvents infertility by promoting fertility practices outside of the female as an individual and in some ways depersonalises her. Her organs are used to achieve conception and although not exclusively, much of the focus is on treatment outside of the body.

Foucault explains that the body and its various parts are understood as being constructed through discourses and practices, widely known as the 'clinical gaze' exerted by medical practitioners (Armstrong 1984:25). The gaze implies a way of seeing; smelling or touching that makes things visible to the practitioner. Once visible the subject or object may be analysed and observed. In this way 'the gaze' conceptualises disease within the anatomy. Foucault's perspective fits into the broader social constructionist approach because it understands medical knowledge not as objective facts but as a belief system shaped by social and political

relations. However it departs from this and is unique in that it suggests that there is not a fixed human body outside of the clinical gaze. A body analysed for infertility is an infertile object in the same way, as organs and tissues constitute a body analysed for organs and tissues.

It is likely that narratives of resistance on the part of the patient will be invisible at the fertility clinic. Resistance is not conducive with successful interaction with the technology offered by the clinic. Biopower, through biomedicine provides the language through which bodies become culturally intelligible. The flow of biopower that occurs between clinic and patient during the course of the IVF process defines the body of the female receiving treatment through her engagement with the treatment. This discourse is one of constraint and doesn't allow for resistance to treatment, not coping with treatment or any other stress responses to the treatment. The reproductive self becomes created within the confines of the narratives of the technology. However, the body is central to the question of who the self is, and this is subjective. Post-structuralist theory describes this notion of subjectivity as one consisting of the 'fragmented' self. The self is contradictory as it emerges through the desires of both the conscious and unconsciousness (Henriques *et al.* 1984). This concept of the self can be used to further analyse the IVF clinic/patient relationship. Different sources of the self become important at different times for the same person. Subjectivity is dynamic and contextual. The recognition of the continual ambivalence of subjectivity can help us to understand how the patient can be both complicit in the IVF clinical process yet perhaps seek to challenge it simultaneously. Counselling when offered alongside treatment can provide a site for challenge. Foucault claims that there is a disjunction between self-knowledge and the interpretation of knowledge by another. His early discussion about this concerns discipline and punishment (Foucault 1977). However from 1981, with the publication of the first volume of *History of Sexuality* onwards, Foucault offers the same theory within a framework that allows also for the exercise of individual agency. Here language has an enabling role, alongside its restrictive role in relation to its inadequacy in reflecting thought processes and feelings. In the context of IVF treatment we can see medical treatment being administered not just on a physical body but on a thinking person residing in a wide

social environment and capable of imparting knowledge and power into their individual treatment.

Power relations that occur as a result of the disjunction between self-knowledge and the interpretation of knowledge by another are evident in the fertility clinic. The meta-level of cultural narrativity with regard to reproduction is evident in the clinical context. Such narratives influence the patients' understanding of her or himself. According to Foucault, when a subject engages in a narrative they are transformed by that narrative. Power produces knowledge through discourse and consequently power structures are inherent in discourse. The reproductive self may be created in narratives of the reproductive technology discourse. Explained in simplistic terms, 'things' become the words used to describe them. John Steinbeck explains this beautifully at the beginning of chapter two of his novel *Cannery Row* "The word is a symbol and a delight which sucks up men, seas, trees, plants, factories and Pekinese. Then the thing becomes the word and back to thing again, but warped and woven into a fantastic pattern"(Steinbeck: 1945:64).

We see in the IVF clinic a site where words are used to categorise the patients who utilise the technology. The reproductive self becomes created within narratives of reproductive technology. Foucault's analysis of the extent to which bodies are inscribed in discursive practice is very apparent here. Individuals become: infertile, donors, surrogates, unfit for treatment due to factors such as age and weight, unfit for treatment because of the welfare of the child conceived, secondarily infertile and so on. Biopower, through biomedicine provides the language through which bodies become culturally intelligible. These categories fail to allow for stress, distress and failure to cope though. Those types of reaction towards treatment are difficult to categorise and disruptive to the smooth working of the institution of the infertility clinic. Counselling when offered to those undertaking the IVF process may offer a site of resistance to categorisation. Counselling may be a site that can attune a patient to how language constructs the self. Self-observation can occur and an analysis of whether or not the construction of the self in the context of the IVF treatment is injurious. Resistance also occurs outside the clinic. In the UK, single and lesbian women have been able to gain access to IVF

treatment through successful resistance. Campaigning has eliminated the previous requirement of consideration of a 'father' and most current legislation refers to 'parent' instead (HFEA 2008). So, Foucault then offers us lenses which view power as enabling in that it offers knowledge, opportunity and potential for resistance despite its prolific and pervasive domination over all of us. Counselling may provide a forum for the IVF patient to become a resistant and non-passive, self-caring individual capable of selecting and determining which treatment is best for them and whether or not to accept treatment at any one particular time. The illness, which is infertility, can be discussed outside of the desires created by the clinic and the social context of the patient. The pressures for the patient that arise out of extreme individualisation of the illness may be reduced. Foucault portrays the self as a project or narrative that has the capability of being constantly rewritten. Counselling can provide a forum for this during the clinical process of undergoing treatment. A Foucauldian perspective contends that it is possible to remove elements of power from members of the medical profession and hand it over to patients. As already discussed, power is not a possession of particular social groups, but is relational, a concept which is invested in and transmitted through all social groups.

Feminist accounts of reproductive technologies have tended to portray female patients as a homogeneous group. Feminist women's health discourse is stymied by persistent assumptions about the stability of a female body and its capacity to designate an integral otherness uniting 'women' (Riley 1988: 105). Foucauldian analysis departs from this. His model of power suggests that male domination is not homogeneous and static, but rather changes in response to the resistances of women. He suggests that power structures create discourses. However there is neither a dominant nor dominated discourse but a 'multiplicity of discursive elements that can come into play in various strategies', whereby there might exist 'different and even contradictory discourses within the same strategy' and discourses might circulate without changing form from one strategy to another (Foucault 1981:100-2). Through this analysis of discourse the female body can simultaneously be positioned as a site of liberation and oppression in its relationship to IVF. The patient is never a uniform entity. Foucault proposes that



'the self is not given to us, I think that there is only one practical consequence, we have to create ourselves as a work of art' (Foucault 1983:237).

Through this recreation of us as individuals, comes the possibility of resistance and social change. Using Foucault's interpretation of biopower can help us to understand the myriad of local practices of power surrounding IVF and the clinic setting and the influence upon the patient. Foucault denies the unitary standpoint in relation to social theory and argues for a decentred approach to individual identity and social formations. The patient can simultaneously be dependent upon the technology and independent of it at various times during the treatment. A patient during treatment may contain multiple, shifting and often self-contradictory identities. Effective public health policy can channel the relations of power between the patient and the clinic more equitably than in clinics that operate in a climate of non-regulation.

Through Foucauldian lenses one way to view public health policy regarding IVF, is that it is motivated by concern for the health and wellbeing of babies and their mothers. IVF treatment offers reproductive choices. These choices are highly individualised. Foucauldian analysis allows us to see medical treatment being administered not just on a physical body but also on a thinking person capable of imparting knowledge and power into their individual treatment. The body in this way is a site of political struggle. Foucault reveals to us a concept of local power, and local workings of discourse on subjects and subjectivities. We can situate IVF patients within this concept. Within the context of the discourses surrounding their fertility options users of IVF are individuals making choices about the reproductive medicine available to them and paying for these services. Patients and their partners firstly make decisions to engage with the technology and then often are able to make choices about the type of service available to them. This is relevant where clinics offer single or multiple embryo transfer as a choice. Users of the service also decide when to disengage with it. Counselling can be a site of local power and a situation whereby to consider the various treatment options and discuss the array of choices that any patient may be faced with during a treatment cycle. Through counselling we can view local workings of discourse on subjects

and subjectivities. When analysing IVF and reproductive choices we can consider IVF as empowering individuals in their reproductive choices. This enables a model of the patients as autonomous selves/subjects and channelling power to women and their partners as reproductive choosers, rather than merely reproducing. This element of choice and the notion of autonomy is valid and relevant with regard particularly to a woman's reproductive choice to accept single embryo transfer, as in many instances this is a further reproductive choice.

In summary, biopower theory draws our attention to the fact that IVF, and the health policy surrounding it, is pursued inside of mechanisms that are attending to the reproduction of the body politic and that power relationships are fluid and unsymmetrical. Such regulation may be seen to be primarily consistent with political investment in 'healthy' reproductive bodies suitable for exchange in the labour market. Effective public policy will also allow the mechanisms of reproductive technology to function with minimal costs to the public health care system. Foucault argues that disciplinary power was essential to the development of modernity in that it made possible the controlled insertion of bodies into the machinery of reproduction. IVF's parallel contribution has provided an instrument for women's bodies into the machinery of reproduction (Sawicki 1991:68). However, effective public policy can also support efforts to create health care institutions that enable families to structure childbearing around each individual's needs. This is important because the technology inherent in IVF is developed by experts, in contexts where scientific and medical authority may be wielded without sufficient attention to democratic decision-making. Also, IVF has overwhelming powers of social control as a disciplinary technology because it can incite desire and the attachment to social identity. Public policy can be a strong and effective mechanism for resistance. For my study 'resistance' to the overwhelming power of the technology may be channelled and explored by patients who may be fully immersed within the medicalised institution of the IVF clinic through the statutory provision of counselling. My investigation focuses on UK public health policy, which promotes safer pre and postnatal health outcomes through restricting numbers of embryos transferred and promotes patient autonomy through the offer of counselling in IVF clinics during the treatment process.

## CHAPTER SIX

### RESEARCH METHODS

**My research methods are broad and occur from and out of the direction that my research took. As my research project developed I discovered different reference points to explore and dissect the complex problem of multiple births occurring from IVF. This resulted in a multi-sited organisation of flexible design qualitative research. I conducted background field research, look at figures, documents, the Internet and conducted interviews. I used this multi-sited or mixed method critique to examine the juxtaposition between user experience and policy and practice discourses. Using such methods enabled me to gain multiple perspectives. Each of the methods or sites adopted in this investigation sheds light on the problem in a different way and not one of them is 100 percent comprehensive. However, when put together they form a comprehensive analysis.**

This chapter explores the research methods used within this thesis. The focus of this study is on the global phenomena of multiple births. Multiple births occur as a result of widespread use of IVF practices and my investigation aims to be an analysis of public policy suitable to promote effective regulation in the United Kingdom. As a resident and IVF patient of IVF in Canada I was fortunate to be able to analyse the multiple birth issue in more depth through visiting IVF clinics, hospitals and support groups. These visits consisted of observations and discussions with doctors and patients. I attended many patient support meetings in Toronto and studied patient support as a medium for helping IVF patients in conjunction with reducing multiple births. Repeated discussions with patients emphasised a general disappointment with the information available to them and with the support offered at the clinics they attended. To explore patient support in

the UK I contacted clinics in order to discover the type of support that they offered patients. I also interviewed counsellors who worked at IVF clinics in the UK. After this, I analysed patient opinion by entering infertility support sites on the Internet. As a result of these various lines of enquiry, a mixed qualitative method strategy, using multi-sited research was adopted. This chapter outlines this methodology.

## 6.1 Discussion of Research Strategy and Design

In developing a research proposal any researcher should consider 2 questions: 1) What methodologies and methods will we employ in the research we do and 2) How do we justify the choice and use of such methods and methodologies? The answers lie in the purpose of our research inquiry, as it is important to find a process capable of fulfilling it. This leads the researcher to a fuller examination of their topic. Doing so enables the researcher to be able to address what Crotty describes as the “four elements” of social science research. These four elements all inform one another. Crotty describes these as: 1) Methods, 2) Methodology, 3) Theoretical perspective, and 4) Epistemology (Crotty 1998: 5).

Methods are the concrete techniques and procedures that I used within my investigation. My methods arose from the nature of my investigation and involved participant observation within clinics and hospitals in Toronto, Canada. To expand my knowledge about the UK and global context of IVF and multiple births, I studied online resources, journals and texts. This developed into a discussion of support services in the UK through telephone interviews with counsellors working in IVF clinics in the UK. To gain a patient perspective I was involved as a non-participant observer in an online infertility network chat room.

My methodology was the strategy behind my choice of methods. I sought to uncover the meanings and perceptions from patients involved in the IVF process. I also wished to enquire about experiences of support counsellors within the clinic. Because I wanted to see things from the perspective of the participants I carried out unstructured interviews during my role as a participant observer in the field of the clinic. My interviews with counsellors were semi-structured to allow the

counsellors' views and opinions to prevail. When entering on-line infertility support forum all of my non-participant online observations were non-directive in order to allow full revelation of patients' attitudes toward the treatments that they were experiencing.

My theoretical perspective is primarily to take a social policy orientated analysis. The analysis of HFEA policy pertaining to multiple births and IVF was primarily analytical as such involved the gathering of knowledge. After gathering knowledge, the secondary purpose of the investigation was policy recommendation. I wanted to explain policies and their context and development. I did this by gathering information about policy in the UK and placing this policy within an international context. My enquiries composed of telephone and email conversations with the HFEA as well as online, journal and text analysis. I attempted to clearly document the policy, as it exists. I interviewed counsellors and took account of patient opinion in the UK and Canada. Although I explored a variety of techniques and approaches in my data collection, the resulting analysis can be conceptualised as systematic and documentable (Coffey and Atkinson, 1996). Secondly my analysis for public health policy is prescriptive and involves recommendations surrounding the formulation of new proposals for this policy. The theoretical perspective behind the social policy analysis has both a contextual and constructionist approach; its scope is macro in scale and aims at explaining the contextual factors of the policy process. I examined the personal, political, economic and socio-cultural factors influencing the social policy. Although my data are connected to specific experiences surrounding multiple births, in writing a public policy recommendation I am not writing simply about the subject of multiple births but I am writing to a specific audience: policy makers. Therefore the data are positioned in a broad social context whilst simultaneously primarily attempting to give a voice to the users of IVF as a medical service.

Michelle Fine may describe my attempt to give voice to IVF patients as 'Ventriloquy' (Fine 1994:17). She describes this as the telling of truth without gender, race, or class stance. She feels that one condition of the telling of the truth is its anonymity. As a social researcher I sought patient voice by listening to their

experiences at the clinic and reading their stories on-line. There was a biographical dimension here to my research. I was concerned with the observing, reconstructing and retelling of people's lives. In seeking to understand a particular social world I was attempting reproduce the stories of the people in that world. In writing and representing the social world through both face-to-face interaction and by on-line observations I was both reproducing their lives and analysing them. This allowed me to subsequently 'cast through their voices carving out pieces of evidence to select, edit, and deploy' (Fine 1994:22) to substantiate my argument as a piece of public policy recommendation. My material was simply a collection of evidence concerning the topic of multiple births at a given period in time in Canada and the UK. This meant that this part of my research was fairly unstructured and described the experiences of those that chose to share them. The type of research that resulted appeared to encapsulate what Denzin and Lincoln may describe as a style of research 'characterized by reflexive, experiential texts that are 'messy, subjective, open ended, conflictual and feminist influenced' (Denzin and Lincoln, 1994: 559).

The epistemological element of my research concerns the matter inherent in the theoretical perspective. It concerns the philosophical grounds for my decisions behind the types of knowledge that I chose to include within my investigation. Here lay my decision to introduce a Foucauldian stance. This epistemology understands that truth comes into existence through one's engagement with any one social reality. I wanted my investigation to acknowledge that meanings are constructed in different ways with relationship to the same phenomena i.e. Multiple births. This is a core assumption for my investigation and simultaneously explains the arrival of the 'problem' of multiple births and my proposed solution to minimise it. The understanding of knowledge from this perspective explains why patients (and clinicians) may have constructed one meaning of multiple embryo transfer and how a counsellor may be of assistance to decipher, explore and explain these meanings. From a feminist perspective counselling may also be of value in that it provides a venue for a deeper exploration any woman's role as a mother. Michelle Fine is of the opinion that it is "a feminist task to provoke a deep curiosity about what is inevitable, immutable and natural" (Gitten 1994:25). Pregnancy,

childbearing and childrearing may all fall into these categories.

Using this theoretical perspective as a backdrop my investigation aims to analyse my response to IVF and multiple births, some patients' and counsellors' responses and place them within a wider social policy context. Here I used data from fieldwork, interviews and on-line observation. When the time came to analyse these data I was able to understand them within the narrow context of the multiple births issue. However, the data also became personalised as the knowledge inherent within it become translated by me and became my 'truth'. I made decisions about and connections with the data I had collected. I, along with the advice of my supervisor was responsible for discovering themes and patterns, deciding what went where in a narrative account, what was significant, important, salient or typical. My analysis related to how I felt about the data, the fields that I visited, the people within those fields and my personal relationship with the investigation and its processes. The resulting truth of my data developed in a Foucaudian fashion out of my relationship with the data.

6.2 Background Research: data collection to establish my research question.

'Insider Research': Observational Data, Exploration and Personal Experience

My investigation of multiple births has been influenced and informed by insider research. Within this study, I, the IVF patient was able to utilise the opportunities offered by participant observation. The clinic where I was an IVF patient was part of a busy group of clinics in the downtown area. As a patient, I, the researcher had access to patient support groups and to some professional medical specialists. In order to maximise the opportunities provided by the participant observation research method, field-notes were made and where feasible. The research that took place was background research. It took place in Toronto, Canada between 2002 and 2004 before formal registration in 2004 with the University of Exeter. Therefore no ethics approval was given. This background research formed the basis and motivation for the eventual study and the results of the data gathered through participant observation as an insider in the field, are integrated into the thesis. The observations that I made whilst in the role of participant observer

resulted in my eventual investigation of patient support systems and their potential relationship with health policy to reduce multiple births.

During my time in the field, I conducted interviews and observations of persons involved in the IVF process. I spent many years as a subject of the IVF procedure and as one identified what I perceived as limitations and difficulties surrounding the technology. I was shocked by the aggressive transfer techniques offered to me. High numbers of embryos were replaced and information about numbers only given at the very time of transfer verbally by the clinician transferring them through the needle. This was followed by a presumption of fetal reduction should more than two (sometimes three) be replaced. The nature of operation of the clinic I attended meant that patients were not given fixed appointments. We showed up and waited several hours on a first come, first served basis for our blood work, ultrasounds and other procedures. This happened 7 days a week. Because of this, I spent hours and hours in the waiting room of the IVF clinic and was able to talk to many other patients about their experiences of the procedure. All patients were given aggressive transfer techniques. When talking with other patients it was clear that the most difficult part of the IVF process was the lack of support and information at the clinic. Information about the technical processes we were subjected to was only given on a written sheet in language very difficult to interpret and clarify. There was confusion about which processes any patient would be subjected to and why. It was clear that more patient support was needed at this clinic and that clarification surrounding multiple embryo transfer was especially important as a high percentage of the clinic's patients who were lucky enough to conceive were subject to complications surrounding a multiple gestation and birth or stress and complications surrounding a fetal reduction, both of which are unnecessary side effects of the IVF procedure.

I was able to interview an obstetrician at Sunnybrook and Women's College hospital in Toronto. This doctor was also the chairman of The Society of Obstetricians and Gynaecologists of Canada's working group on multiple births. His opinions provided insights into how babies who are products of IVF were affecting the health service in Toronto. I was also able to interview the director of a



large privately run IVF clinic in downtown Toronto. Through the interviews it is apparent that the doctor working in the public sector had very different opinions about single embryo transfer than the private sector doctor.

Additionally to complete my research I spoke with several patients who have carried a multiple pregnancy as a result of IVF. Through my visits to clinics I became familiar with an infertility educator at Women's College Hospital in Toronto who runs a support group once a month for women who have become pregnant after infertility. The support group invites these mothers to come and meet with other women to discuss feelings, issues and solutions in a supportive confidential environment. The infertility educator invited me to attend the support group meetings.

Participant observation is a method of examination where the researcher can assume a role, or a number of roles, participating in the events being studied. The researcher is more than a passive observer, becoming integrated into the situation, which is the subject of their study. Although this method offers a unique opportunity to collect data, it also presents significant difficulties. Distinct opportunities include the ability to collect evidence from the "inside" of the case study rather than as someone external to it. Some argue this offers an invaluable opportunity to produce an accurate description of a case study phenomenon, in this case a study of the relationship between patients and the clinics they attended for IVF treatment in Canada (Yin 2003:94).

The aforementioned significant difficulties relate to the potential for the production of biases. As the observer is integrated within the situation of the study there may be occasions where positions are taken that are contrary to the interests of good scientific practice. For example, the researcher may need to assume the position of an advocate, rather than an observer. This occurred to a small extent during my participation in the patient support group of the IVF clinic where I received IVF treatment. The participant role may require too much time and attention in relation to being an observer, resulting in logistical issues, as the researcher may not have enough time to make notes or raise questions. This often occurred when talking to

consultants and other medical professionals during my own IVF treatment. In these instances I had to sometimes wait a considerable time before being able to record my experiences. My field notes provided a structure and a purpose to day-to-day field experiences of being in the IVF clinic. They were a stepping-stone to being a final published account of the reality of some patient experiences that I encountered in the field. At that time many of my field notes were records of private thoughts and feelings. This 'raw data' was preliminary and do not appear in the thesis nor did I share them with my thesis supervisor. I feel that my personal experiences are reflected in the text rather than being present in them and in that capacity present a source of insightful analysis.

Participant observation be very time consuming, particularly if the subjects studied are physically dispersed over a large area, and it can pose ethical dilemmas for the researcher. Finally, access to organisations might be difficult (Yin 2003:96). For me, access to the IVF clinic was no difficulty given that I was a legitimate patient consumer of the services available there. My role as an insider researcher did make my patient role more time-consuming because I spent extra time attending support groups and talking to patients that I may not have necessarily engaged in had I not been interested in investigation of the field. I was fortunate the clinics and hospitals that I attended were not dispersed over a large area but contained within the downtown area of Toronto. The only ethical dilemma I recall encountering concerned disclosure of research status. I approached this by disclosing my status as a potential research student whenever I felt this to be appropriate.

As a researcher I did pay attention to my image and the way that I appeared to patients, clinicians and clinic staff. I wanted to appear friendly and approachable and allow any potential encounter to be an opportunity for conversation and information gathering. This was context dependent and less easy to do within hospital setting where I was under clinical observation myself. In what they describe as 'impression management' (clothes, the use of props, speech), Hammersley and Atkinson consider the consequences of managing identities in the field. They emphasize how the ethnographer manages the self in order to

conduct fieldwork successfully. They are of the opinion that ‘the researcher must judge what sort of impression he or she wishes to create, and manage appearances accordingly. Such impression management is unlikely to be a unitary affair however. There may be different categories of participants, and different social contexts, which demand the construction of different ‘selves’” (Hammersley and Atkinson, 1995: 87). I felt that in instances where I took my children into the IVF clinic with me I was more attractive to the other patients in the waiting room. My children (conceived by IVF) were both valuable and desirable. Other patients wanted to talk to me about them. Other patients treated me differently when I did not bring my children. At these times many patients displayed an attitude of indifference and then I was approached and spoken to far less. During these times it was I who had to make cheerful and friendly conversation in an atmosphere that often reflected the fragility and sadness of patients amplified by the antisocial hours of our gatherings. We waited for the clinician and other clinic staff to administer our treatment plans very early in the morning 7 days a week and conditions outside were dark and cold and snowy in winter months.

My experiences as a user of IVF services were fundamental to the shape and form of my subsequent research. I was privileged to be able to conduct ‘insider’ research because I was recipient of IVF services. Insider research refers to when researchers conduct research with populations of which they are also members (Kanuha, 2000). Consequently the researcher shares an identity, language, and experiential base with the study participants (Asselin, 2003). The complete membership role gives researchers a certain amount of legitimacy and/or stigma (Adler & Adler, 1987). This insider role status frequently allows researchers more rapid and more complete acceptance by their participants. Therefore, participants are typically more open with researchers so that there may be a greater depth to the data gathered. I found this to be the case in the context of the IVF clinic in Canada. Patients were willing to chat with me in the waiting room because I myself was a patient. I also had unique opportunities during my own consultations with clinicians and other clinic staff to discuss topics relevant to my investigation. I was lucky to be pregnant 3 times as a result of clinic treatment. After 3 months for each pregnancy I was discharged from the private IVF clinic where I conceived the

babies and became the recipient of public health care. As a pregnant patient and subsequent parent of multiples I was also given a unique opportunity to talk to clinicians and hospital staff about multiples and experience neonatal premature baby care first hand. I feel that many patients would never have shared their experiences with me if I were not also a patient.

The stigma that Adler and Adler describe refers to the view of outsiders, who might see this role as creating a heightened level of researcher subjectivity that might be detrimental to data analysis and even collection. This is because the so-called conventional wisdom of ethnography has been premised on a duality of observed and observer. The observer-ethnographer is able, and encouraged, to adopt the position of an ignorant outsider. Adler and Adler asserted that the distinction between researcher and participant has 'traditionally existed more strongly in theory than in practice' and that 'objectification of the self has occurred in the analysis rather than the fieldwork' (Adler & Adler, 1987: 85). This statement felt accurate when I was a patient of the IVF clinic. The clinical environment suited an analytical assessment of the procedures involved and the patients' interactions with them. However, I feel that this statement by Adler and Adler underestimates the emotional stress that the researcher may experience in the field. This was especially apparent for me in prenatal emergency care where I was a patient for one month due to complications surrounding my pregnancy. Here mothers had repeatedly lost babies who were miniscule and I was surrounded by many of those living fighting for their lives. The emotional distress was repeated in the neonatal intensive care ward where my babies were placed after birth. Again there was a first hand exposure to loss, death, bereavement and the fight for survival. During my times in both of these environments I felt that I was a patient and not a researcher. It was after much time that I was able to reflect analytically upon the experience. It appears from my experience in the field that context influences the objectification of the self. This relationship between researcher and context is dependent upon the experience of multiple relationships between the researcher, self, the field and the subjects of the field. My experiences in some of these field contexts can be partially synthesised by comment that 'field researchers do not always leave the field physically and emotionally unscathed, and they rarely leave

unaffected by the experience of research' (Hammersley and Atkinson, 1995: 120). This commentary emphasises the emotional stresses of fieldwork and hence the importance of self-management.

In his book 'Real World Research', Robson offers practical advice to manage conflict in the field during insider research. He suggests that the researcher should: a) Try to foresee likely conflicts, b) Make a plan to deal with them, c) Record responses, and d) Where possible get the collaboration of researcher colleagues from outside the situation (Robson 2002:383). I tried to foresee likely conflicts and considered that the main conflict would be my emotionally charged sympathetic response to IVF patients and mothers. This happened mostly in prenatal and neonatal hospital care units and not the IVF clinic. The second conflict appeared when interviewing my own private IVF clinician about and questioning his conduct in regard to multiple births yet simultaneously needing to engage his expertise in using the IVF service. My plan to deal with these conflicts was to engage coldly in conversation, take notes and analyse the field notes at a much later date. This time-lapse allowed me to disengage with the circumstances surrounding the field research. I was unable to get the collaboration of research colleagues as this part of my study was background research and I was not as yet a registered student at the University of Exeter.

As previously mentioned, traditional wisdom surrounding the status of the insider researcher emphasises a duality between the observer and the observed. However my experience was that, because I was a researcher with a deep connection to the other infertile patients at the clinic I attended, I was motivated by personal interest to explore exhaustively their accounts of the treatment process. Consequently I was always aware of this emotional connection to the field and the relationships that I made in it. My journey in the infertility treatment was parallel to the patients I sought to study. During the time I spent in the clinics I felt that my emotional engagement was necessary for the motivation to embark on my subsequent investigation and accounted for both the completion and the quality of the final project. This is because there was an intrinsic sense of connectedness between the self and the fieldwork. My experiences of infertility, infertility treatment,

pregnancy and childbirth and parenting of multiples and my status as an infertile woman and later as a mother were central to the ways in which I experienced the field. Any relationships with other female informants and the IVF clinic and hospital were predicated on our shared physical state. Each experience was dependent upon cultural context, time and space. As a result of these interactions as a researcher my immediate experience of pregnancy and memories of infertility treatment, pregnancy and childbirth have been shaped by the advice, interest, roles and biographies of all of the informants that played a part in the background research that I undertook whilst in Toronto, Canada. My constantly changing body state and status was a significant aspect of my field role and contributed to the quality of the relationships that I formed, as was the presence or absence of my children in the field. Coffey summarises the unique, informative and very special relationship that a researcher may have with his or her own body as a two way process when she states, "We are observing, interpreting and analysing the bodies and body perspectives of others. At the same time we should analyse and use the physical ways in which we experience fieldwork, rather than denying them or simply taking them for granted" (Coffey 2002:76).

My experiences as a researcher placed me within a variety of settings that enabled me to have access to information pertaining to my position and a deeper understanding and appreciation of all mechanisms involved in my journey through the infertility treatment process. My experiences demonstrated that as a researcher undertaking qualitative fieldwork I needed to be prepared to become part of the interactions of the setting. My role as an 'insider' facilitated this. At a basic level this reinforces an underlying perspective that everyday life is enacted through social interaction. While this is a guiding principle of qualitative fieldwork, it is easy to lose sight of the fact that those relations and interactions implicitly include the researcher, as well as the researched. As an 'insider' qualitative researcher I was uniquely prepared to enter into, as well as document this social interaction in the field. Denzin summarises this type of experience in his acknowledgment of his contribution to ethnographic thinking. He states that his work engages with the premise that 'we are our own subjects. How our subjectivity becomes entangled in the lives of others is and has always been our topic' (Denzin, 1997: 27).

My research looks at patient support as a way to improve the patient experience of IVF and as a possible tool to increase the viability of single embryo transfer. Information gathered from IVF patients in Canada led me to believe that transparency relating to procedure and outcome was vital for decreasing patient anxiety. It also became apparent that: prospective parents needed additional support in what was considered to be a commercially orientated, uncaring environment. These patient insights demonstrate, along with the result of studies about the outcomes of mental health support and fertility (see chapter 6) that the success of such health policy surrounding IVF could be patient driven to reflect their needs as well as science driven, reflecting advances in infertility biotechnology. Some women come to IVF depressed with low feelings of self-worth. When this happens, women may open themselves to a 'paternalistic interaction with the physician' (Bonnicksen, 1995:55). Paternalism has a history in medicine and a patient may accept a doctor's recommendation to undergo the IVF procedure without full discussion of the consequences or of the alternatives available.

### 6.3 Policy Analysis

This research can take a number of forms, including analysis of newspapers, company reports and committee minutes, as well as academic journals and textbooks. It can also include non-written sources such as tape and video recordings, DVDs and CD-ROMS (Denscombe, 2007:12). I undertook extensive online searches of all academic journals relevant to my investigation. In addition I searched HFEA, RCOG, ESHRE, ASRM and SOGC websites. The construction of a policy review is also a form of policy analysis. The policy review within this study initially used documentary research to look closely at IVF practice in the UK and then explore the position of the UK in a global context. Before starting this investigation I was a patient of IVF in Canada. This experience led my investigation by opening my perception to the fact that both multiple births and patient support lacked attention in clinics and in public policy.

In Canada at the start of my study there was a lack of regulation and policy however mechanisms were in place to introduce a legislative framework in this country. I found the United States to be completely lacking in any public policy regarding IVF clinics. Turning my attention to Europe I found secondary statistical data from IVF clinics available from many countries. In Europe ESHRE publish such reports in the journal 'Human Reproduction'. Their data enabled a comparison of embryo transfer numbers in the UK, which is required to comply with The Human and Fertilisation and Embryology Act, and the rest of Europe, where legislation exists for many countries. I felt that this data would provide me with data to compare, measure and make comments about how successful policy was in the UK. This data demonstrated how embryo transfer rate figures compare in IVF clinics that regulate multiple births to those that had no regulation. From my data analysis it was clear that UK health policy with regard to multiple births was influencing the multiple embryo transfer rate, but not at substantial enough levels.

In the UK, The Human Fertilisation and Embryology Act requires every clinic to publish an annual report of its results. The HFEA publish these statistics. Every clinic is licensed and visited by inspection teams to assure compliance with the law. The initial treatment data I looked at covered the period between April 1st 1998 and March 31st 1999. Data are usually published at least 2 years afterwards to allow for pregnancy outcomes to be collected. Also, additional time is taken for the HFEA to collect, organise and analyse the data and prepare the report, which is then made available to the public. The quality control steps to ensure data accuracy are high in the UK. The HFEA inspects all licensed IVF treatment centres annually and keeps a register of all treatment information. Failure to comply with the HFEA's guidelines for the operation of these clinics (which includes submission of accurate data) can result in revocation of a license. Unfortunately in the rest of Europe at the start of my research no clinic was statutorily required to publish information about its activities. However, the European Society of Human Reproduction and Embryology (ESHRE) collect data from a large number of IVF clinics in Europe and I was able to gain access to statistics for 1998. I later revisited the data for IVF cycles undertaken in 2005 and 2009. The 2009 data were available in 2013 and are the most current statistics available to me. The data are



incomplete and generated through different methods using different definitions in different countries. Interpretation of the figures should be approached with caution. Nevertheless, such information helps to further provide insights into the global situation with regard to multiple births in IVF clinics.

#### 6.4 Observational Data and Documentary Evidence

My investigation concentrates upon public policy regulations in the United Kingdom. I collected information about support systems offered to patients at clinic level from each clinic throughout the United Kingdom. I contacted each clinic in the United Kingdom by email or telephone. I asked them if patient support was available at their clinic and if so in what form. I also asked for further information about the type of support available. Many clinics mailed me this information. The support systems that UK clinics offered included group therapy, counselling, published information and stress reduction techniques such as yoga and acupuncture. I found support to be highly variable across clinics and regions, although all clinics complied with the minimal public policy requirement to be able to offer the patient counselling and if accepted recommend either an on-site or off-site service.

I compared the level of patient support to published birth rate figures from the clinics I contacted. Published birth rates for each clinic in the UK are available from a central register from the HFEA. These figures are also known as “success rates”. My aim was to see if any relationships could be found to support the hypothesis that support for patients can decrease stress and distress levels and hence improve the effectiveness of the treatment. Because I was unable to isolate the variables of support and success I could make descriptive observations about any patterns I could find rather than direct relationships.

#### 6.5 On-Line Non-Participant Observation

I entered 3 public online UK support forums as a non-participant observer. These were named ‘Fertility Friends UK’, ‘Infertility Network UK’ and ‘IVF Infertility UK’.

Two of these were recommended to me by the HFEA and were the only major forums in the UK that specifically supported patients undergoing fertility treatment. Other sites did exist but covered related issues such as life with children after infertility or experience of secondary infertility. The on-line support forums were comprehensive electronic archives of written material representing infertile women's opinions, concerns, and desires. Material on these venues can be a rich source for researchers interested in understanding the experiences and views of people and patients. Qualitative analysis of material published and communicated on the Internet can serve to systematise and codify needs, values, concerns, and preferences of consumers relevant to health and health care.

The universe of Internet support that I wished to access was online sites that were accessed specifically by patients in UK clinics. Although my overall investigation has been international, my policy recommendations are currently focused upon the UK. There were three ways to gather my sample of sites. Firstly I contacted every IVF clinic in the United Kingdom to find out if they offered an online forum of support, specific to their clinic for patients. I did this by email. Surprisingly, only one of the clinics in the UK provides this type of specific support. However this clinic is the largest in the UK and boasts eleven sites nationally. Each location uses the same online forum, although patients have the option to use location specific parts of the site. Other clinics explained that they offered a generic online enquiry service or that patients could email or telephone questions to nurses or other clinic staff. One group of clinics offered a 'dear doctor' email services that enabled patients to contact the managing director of the group of clinics. Many clinics referred patients to national on-line support. The mostly commonly recommended, according to my enquiries, was "Fertility friends, UK". The second most commonly mentioned site by clinic staff to patients was "Infertility Network UK". Many clinics referred patients support queries to their in-house counselling service or support group. Other clinics were currently investigating this type of support forum with a view to introducing it at a later stage or thought that this type of support was 'a good idea'. One clinic was adamant that direct access to the nursing team for patients undergoing treatment was superior to online support as

the 'personal touch is very important at this stage'.

Secondly, to gain my site sample, I contacted the HFEA to find out which sites they recommended for on-line support for patients undertaking IVF. They recommended Fertility Friends UK, Infertility Network UK and IVF Infertility.com. Two of these were the same sites that were recommended by the clinics that I approached. Lastly, I put in IVF and Infertility Online Support UK in an online search engine. Several sites came up but not one offered a chat room or online forum specific to my investigation. There were several sites for parents who had already given birth to families using assisted conception and a site for parents of multiples, which unfortunately had no chat room. Another site could be accessed by or give information about fertility professionals, this also had no online forum. This meant that my final sample of online forums consisted of four sites. The first of which was associated with a chain of UK major IVF clinics. The other three that are general UK online sites, these three sites were all endorsed by the HFEA.

For all of the sites that I entered I used the search terms 'single embryo transfer' and 'multiple births'. My search period was between the years 2002 (the year in which I started my initial background investigations) and 2011 (the year of the search). I extracted all of the narrative pertaining to these topics and set them down in separate folders in Microsoft word documents. I separated more general discussion surrounding multiple births from more specific views, discussion and opinion about SET. From these two categories I then thematically coded data according to the topic. Topics were 1) Experience of multiple gestation/birth 2) Experience of SET 3) Opinion of SET 4) Opinion of HFEA policy/experience of SET consultation 5) Financial Issues. These themes were chosen because of the high amount of discussion generated around these topics. I analysed the data by pondering these themed documents and choosing some examples of narrative from each of the major themes. I chose examples for all themes from all sites where possible. However some sites generated more traffic and therefore more discussion than others. The site 'Fertility Friends' was the busiest. In 2011 it had 71 724 total members. There were 604 posts about multiple births and 807 posts about SET. The forum operated in such a way that a member would post a

synopsis of their situation and other members may read and if they choose to comment or reply to their post. When I searched a general search for 'single embryo transfer' the 807 posts all appeared in number and date order with any responses that they may have generated. For example, one heading read Topic: Double embryo transfer or not?? Honest thoughts please. This was read 1208 times. This posting read:

"Many thanks for all your kind responses and for taking the time to read my post. I think I knew what most responses would be but I needed to hear them. I am so sorry to read of those of you who have had tragic experiences and I wish you all the love and luck for the future

I have tried to talk to DH (Donor Husband) several times this week about my concerns but he has his own mind made up on the decision - he feels I am being 'negative' about worrying about a double embryo transfer and creating problems that may or may not happen. He has the general theory of go with it and then deal with any problems if they arose- I keep saying we don't even know if this is going to work anyway. I guess I was trying to be sensible and think about things in a logical manner considering my past. I guess we have a couple more weeks to think about things and make an informed decision. If my DH will listen and think in a sensible manner

Many thanks again for all your responses xx"

One response to this post read:

"Don't be too down about your husbands response - mine said almost the same!

In case it is helpful to you, when I was hunting for information on

this subject I found a medical research paper that demonstrated that for a second pregnancy, the chances of premature delivery of twins is influenced by whether or not the first born child was early or term. So the woman who has delivered preterm before is MORE likely to deliver her twins before the average twin gestation, and the woman who had a term delivery before is more likely to deliver her twins AFTER the average twin gestation.

That said, as you will know, this all has to be balanced up with the chance of conceiving twins in the first place.

Also give a thought to single blast transfer. Apparently the chance of pg (pregnancy) in single blast transfer is quite a lot more than half the chance of pg in dual blast tfer (transfer). And for younger, fertile women (which I'm not!!!) who produce a good number of embryos, the chance of pg with single blast tfer is supposed to be very similar to dual embryo tfer.

It's a very tough decision I know.

Best wishes”

(Fertility Friends 2011)

Each member has an option to give details about their personal infertility journey online. These appear after any post they make. The posts were sometimes useful in that they gave me an indication of the extent of treatment experience that surrounded each personal commentary or post. The personal details from the above posting read:

Me 31, DH 37, TTC (Trying to Conceive) since 2004 - me diagnosed with lymphoma in 2002 and after intensive chemo warned that we would probably never have children...

1 month of clomid in Dec 2005 – BFP (Big Fat Positive)!! Miracle DS arrived @ 35 weeks.... our dreams came true x

Desperate for a sibling.. 7 months of clomid – BFN (Big Fat Negative)

IVF 1 - egg shared - chem preg

IVF 2 - egg shared - only 1 for us BFN... change of clinic and new direction...

IVF 3 - solely ours at NURTURE.. 2 blasts transferred on 10th Aug - BFP!! Our dreams have come true again!! DS2 born at 32+6 - all well in the end!

July 2011.. shock natural BFP!

Most members post their fertility journey history.

(Fertility Friends 2011)

The second site I visited 'Infertility Network UK', had 2482 members in 2011.

There was no information available about the site's total membership size. There were 105 postings about multiple births and 174 about SET. Members on this site did not display their fertility journey information and were very often anonymous.

The third site 'IVF infertility.com' also gave no information about membership size and offered 319 postings about multiple births and 448 postings about SET for the time frame I searched. Most members identified themselves by name but no other details were displayed. The Nurture IVF Group offered the support forum connected to IVF clinics in the UK. This is based in Nottingham but offers treatment at 11 clinics across the UK. The forum boasted a membership 12939. There were 36 postings relating to my search for multiple births and 59 postings about SET. Members identified themselves only by a single-word name.

While the internet makes people's interactions uniquely accessible for researchers and erases boundaries of time and distance, such research raises new issues in research ethics, particularly concerning informed consent and privacy of research subjects, as the borders between public and private spaces are sometimes blurred (Buchanan 2004). For my research I examined accounts of patient experience of IVF to discover attitudes about single embryo transfer. The resulting biographical

narrative was all at once emotional, complex and personal. However, this qualitative data analysis focused on the content of the conversations rather than the people who contributed. This meant that anonymity was preserved. The sites were all in the public domain.

## 6.6 Interviews

Finally, in order to find out more about support in the UK at an individual clinic level, I interviewed counsellors who support patients before, during and after an IVF cycle. The current counselling apparatus that is statutorily enforced and offered to patients in UK clinics may be or have potential to be a forum to discuss single embryo transfer. Counselling and its function in the clinic may also be useful in consideration of policy to improve IVF procedure generally and decrease stress, distress and depressive symptoms in patients. I intended to conduct non-experimental, qualitative research. This is descriptive research and attempts to summarise what is going on during some counselling sessions in some clinics in the UK. The study recognises the counsellors to be expert informers regarding the counselling provision in the clinics in which they work, and their own experiences and perspectives about the counselling sessions that they conduct. The participants in this investigation were the 12 counsellors attached to IVF clinics in the UK.

After consideration I decided that a select sample would suit my research. This is because counsellors needed to be from clinics that represented all regions of the UK. I also needed to interview counsellors from a variety of sizes of clinic and cover clinics that were private; NHS or NHS, private split in terms of their treatment options. This type of a select sample emerges from a theoretical type of sample as opposed to a statistical more random type of sample: 'Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges'. This process of data collection is controlled by the emerging theory (Glaser, Strauss 2008:105). I had a finite number of fertility clinics to sample from in the UK. Firstly, I separated them

by region. After this I separated clinics by their size and treatment funding options. From here I recruited counsellors working out of these clinics by email or telephone to find willing participants.

I asked the UK fertility clinic counsellors a selection of questions regarding their professional practice. Questions in an interview can be used to collect data relating to what a participant “does, thinks or feels” (Collins 2005: 167). They can also be used to gain an understanding of a particular subject. My interview analysis focused directly upon the questions that I asked the participants rather than upon any emergent themes resulting from the interviews.

The interviews within this study provided the main source of primary data for this research. The majority were formal, semi-structured interviews, although it should be noted that some informal discussions took place with IVF patients and doctors in Canada during the course of the research. These discussions informed the direction of the study and ultimately influenced the findings, although not to the same extent as the formal interviews. This section will concentrate only upon the formal, semi-structured interviews.

Interviews can take a variety of forms involving one, two or a group of people. They can be administered at a distance, for example, over the telephone or using technology such as SKYPE. They can be conducted face-to-face on neutral ground or at the interviewee’s or interviewer’s home or place of work. Each of these methods has advantages and disadvantages. My choice of a telephone interview was due convenience in terms of time and cost. I was able to reach infertility clinic counsellors from across the UK (including Northern Ireland) without the cost or the time that it would have taken to travel to such a variety of locations. I was able to digitally record each interview using equipment at the university and my own computer. The telephone interview has advantages and disadvantages. On one hand, telephone interviews allow you control over the setting and the environment of the interview and you can have prepared notes and information at hand to help you answer questions. On the other hand, telephone contact does not allow you to see or respond to non-verbal cues (body language and gestures,



facial expressions), often important in interpreting the reaction of the interviewer and responding appropriately. Nor can the interviewer see or respond to you, which might limit your capacity to demonstrate your interpersonal skills. Sometimes information that would be given by non-verbal cues needs to be verbalised by the interviewee, or the interviewer will need to request additional verbal confirmation to reinforce his or her impressions.

Interviews can be formal, highly structured occurrences (the structured interview), or be informal and unstructured, with the discussion following an open conversation (the unstructured interview). The interview style utilised in this research, the semi-structured interview, falls between the two extremes. This type of interview can be described as non-standardised (Saunders 2003: 248). Although the same list of questions and areas for discussion were used in all interviews, the questions were targeted depending on the interviewee's interests. The majority of questions were open-ended, although some closed questions were used initially to fully establish each interviewee's role and interests within the sector and identify areas for further discussion. The semi-structured nature of the interviews also allowed areas that were not on the list of questions, but appeared to be interesting to the study, to be explored further.

At the outset of the study I held a conversation with my primary supervisor to identify potential areas to be explored. I then compiled themes within the area of my study into a list and used this to formulate interview questions. The list was influenced by informal discussions with patients and doctors that I had previously undertaken and literature and Internet searches completed previously. My questions were additionally influenced by any findings I had made contacting all the IVF clinics individually in the UK to initially investigate the support services that they offered. The identification of areas of discussion gave me scope to thoroughly explore the administering of patient support with the IVF counsellors that I interviewed, in a structured manner. I was then able to send my proposition to conduct interviews for consideration by the HuSS Ethics Committee (see appendix 4).

## Selection of Interviewees

I choose a select sample of 15 private IVF clinics in the UK. The largest clinic (with the most IVF patients) will be selected from each of the 12 geographical regions in the UK (as defined by HFEA) with two larger clinics selected from both the London and South East regions as they have many more IVF clinics than other geographical areas. I then contacted the counsellor associated with each clinic by email or telephone to inform them of the study and invite their participation in a short telephone interview to ask some questions, which will describe the implementation of counselling at their clinic.

In summary, the process of selecting potential interviewees was multi-faceted, and undertaken whilst carefully considering the research questions and the areas of study drawn up beforehand. In my previous investigation of enquiry into the type of support offered by UK fertility clinics I had been in contact with all 86 fertility clinics in the UK. All clinics that offered IVF as a treatment were statutorily required to offer counselling. For my interviews, I needed to contact counsellors attached to UK clinics and discuss the services they offered, by telephone. The conversations were digitally recorded. After consideration I decided that a select sample would suit my research. This is because counsellors needed to be from clinics that represented all regions of the UK. I also needed to interview counsellors from a variety of sizes of clinic and cover clinics that were private; NHS or NHS, private split in terms of their treatment options. Sixty percent of counsellors in my final sample worked out of exclusively private clinics. The others were mostly a mixture of private and NHS clients. Most NHS clinics also take private patients. Fifty percent of counsellors in my final sample worked out of large clinics, the others worked out of small to medium size clinics. Clinics that required patients to pay for counselling services were all private clinics and tended to be smaller clinics. Those clinics, which offered counselling for free, were both private and NHS clinics and were larger in size. I experienced some difficulties recruiting counsellors to the interview study. Many counsellors that I approached declined to be interviewed. In total my response rate turned out to be twelve out of fifteen interviews. Despite

recruitment issues I felt that the counsellors I spoke to were broadly representative of the counselling population in the United Kingdom as a whole and worked in varied IVF clinic settings. This is because I was able to interview counsellors from a sample of different regions and from a range of work environments. Every region, variation of patient base and size of clinic was represented. I conducted telephone interviews of between 45 minutes and one hour. The interview design was semi-structured and each interviewee was invited to consider nine questions.

### The Interview Process

Once the areas to be discussed and the questions to be asked were established preparation for the interviews began. Participants were initially contacted by email to ask if they would consent to an interview. Sometimes this was followed up with a telephone call. An outline of the nine research questions were attached to the initial emails sent. The attachment made interviewees aware of the broad topics to be discussed and provided information about the funding of the research, contact details for Susan Kelly, the lead supervisor for the PhD, and contact details for the interviewer. Confidentiality and anonymity issues were clarified. Two copies of a consent/information form were then mailed to each interviewee and one signed copy was sent back to the interviewer in a stamped addressed envelope (see appendix 5). On gaining a participant's consent to an interview, arrangements were made for the discussion to take place. I interviewed all counsellors by telephone from the University. Most participants spoke to me from their place of work; the IVF clinic although a few were contacted off hours at home. The date and time of the interview were flexible, to be as convenient as possible for the participant. All interviewees were asked if they would consent to the discussion being recorded by a digital Dictaphone. An Olympus Digital Voice Recorder DS 50 was used for this process. All participants allowed this. The majority of interviews lasted between 45 minutes and an hour.

On commencement of the interview, I introduced myself, explained the interview process, reinforced the confidentiality and anonymity of the process and thanked the interviewee for participating. An overview of the PhD was also provided. At the

end of the interview I again thanked the participant for assisting with the project and confirmed procedures for validating the transcript.

After the interview had been completed the recording was transferred to computer for safekeeping. The computer is protected by password so that others cannot gain access to the recordings. The interviews were then transcribed verbatim directly from the recording. Upon request the transcript was then emailed to the interviewee for validation. This allowed the interviewee to ensure that their comments had been fully understood and correctly transcribed by the author. Two interviewees requested this. The interviewee was also able to make amendments to, or remove sections of, the transcript. Some changes to individual transcripts were requested by some participants and adopted. I felt that these minor amendments did not influence the quality of the data source as they consisted of extra comments that the interviewees wished to add having now been given more time for reflection upon the questions. Where text from an interview is quoted within the thesis neither clinics nor counsellors were identifiable and the participant was contacted to approve its insertion. Participants were emailed the selections with a date by which they needed to contact the author if they wanted the text to be removed or altered. This was the last point at which a participant could withdraw from the process. Contacting interviewees at this point was useful, as during this process some participants offered additional information, which was incorporated into the study, and it also ensured that data were as up to date as possible. Upon completion of the thesis interview recordings will be deleted and all participants will be sent a thank you letter and a summary of the findings.

At the start of each interview I always gave a detailed explanation and synopsis of my research. Then we discussed the content of the guide questions. During the interviews, I was careful to give an interested, but unbiased, response. Most questions were open-ended, although initially some closed questions were utilised to fully establish the interviewee's role and interests within the fertility clinic that they worked out of, and to identify any areas for further discussion. For example, a participant would be asked about the type of support services that the clinic they were attached to provided patients. If they were involved with any other types of

patient support other than counselling their reply would be explored. If a response was unclear the interviewee was asked for clarification. Questions always explored how patient support operated within the clinics that counsellors worked from. With every counsellor I more generally discussed the IVF clinic environment and the fashion in which it is funded. We then talked about the policy with regard to counselling as a support service at the clinic. I asked them about their impressions of the extent of patients' engagement with any service available. Any questions that could be considered sensitive were asked at the end of the interview when a rapport had been established. All of these aspects of the interview process promoted validity and reliability, and are evidence of good practice. The digital Dictaphone enabled me to concentrate on the interviewee, the questions to be asked and the responses given.

Many counsellors told me that the focus of the work at the IVF clinic was surrounding donor gametes. They told me that patients were required to engage in a counselling session with them before treatment could proceed. With all counsellors I was sure to have an in-depth discussion about their opinions of multiple births and SET. Participants were specifically asked to identify how they felt that multiple birth reduction policies impacted upon their professional interactions with fertility patients and their responses were carefully explored. Sometimes topics arose frequently that were not on my list of questions. Two examples of these topics were 1) tensions arising between what they perceived to be a social work role and a counselling role 2) the proposed demise of the HFEA. All counsellors stressed the importance of their service in taking the most important and fundamental issues in their patients' lives and all counsellors (except one) felt that the service had room for improvement in the clinic that they worked out of. I found that counsellors were a pleasure to interview to and rewarding people to engage with because they are professional listeners and talkers.

## 6.7 Analysis and Presentation of Interviews

The analysis of the interviews occurred in three stages. Firstly, they were analysed during the transcription and validation stage referred to above. Suggestions for

further clarification were reviewed, and acted upon where appropriate. If an interesting point had been raised, or a specific point needed clarification, a note was made, and this was explored either through subsequent telephone interview or email to the interviewee.

Secondly, when the interview process was complete further analysis was undertaken. The transcripts were coded according to the questions utilised in the interviews. The list of questions can be found in Appendix 6. I carried out a case-by-case analysis for each interview. This type of approach began with a close reading of each interview for 1) repetition of specific words, phrases and general thought patterns; 2) topics that dominated the interviewee's reports as well as topics that didn't get raised or were avoided. In addition to these analyses, interviewees were grouped according to whether they were working from a private or NHS mix clinic. The size and location of clinic was registered also for a comparison across clinics. From the questions used in the interviews themes arose. I was able to identify key themes arising from the interviews as a result of the counsellor's comments. Themes either related to the 1) Clinics 2) Patients or 3) Counsellors 4) Multiple Births. Discussion surrounding the IVF clinic focused on the physical environment of the clinic and the services and information that the clinic provided to the patient in the form of cycle support. Findings surrounding Patients concentrated upon the counsellors' opinion of the patients' attitude towards, engagement with counselling as well as some examples of patient experiences. Discussion about the role of the counsellor themselves explored the type of support that each counsellor offered within the clinic that they worked from. Finally, narrative surrounding multiple births focused upon each counsellor's experience with patients who were carrying a multiple birth or a patient's attitude toward the prospective of a multiple birth.

In order to complete this exercise a Microsoft Word document was created for each counsellor. I recorded each counsellor's comment for each question asked. From this a Microsoft word document was created for each theme. Comments relating to each theme and were then inserted in the appropriate place. Some comments were included under more than one theme. Suggestions for clinic practice arose

from these themes. These policy recommendations for clinic practice are summarised in Chapter 9.

In addition to the coding of interview responses a third stage of analysis was undertaken. This focused upon a face-to-face discussion about my preliminary findings from the interviewees with infertility counsellors from BICA that I did not interview. When initially approaching counsellors about my research I had additionally notified the BICA about my research. BICA had asked me to write a summary article about my findings for their journal. I was also invited to present my findings at their South West regional forum. During this stage the format of this article became clearer and I was able to commence writing for both the article and presentation. During this writing stage I made constant referral to the interview material and coded responses. Later, interview responses were written up to constitute a chapter of my thesis. Some direct quotations were taken from interview transcripts and inserted in relevant places in this chapter. However, no interviewees or clinics were identified in either the journal or thesis summaries. Lastly, I sent a summary of my investigations in the UK to the policy manager at the HFEA who manages policy regarding elective single embryo transfer and other general multiple births issues. Again, no interviewees or clinics were identified in any of this thesis summary material.

## 6.8 Ethics for Interviews

Ethics are a fundamental consideration for any research project. Research ethics can be defined as: The appropriateness of the researcher's behaviour in relation to the rights of those who become the subject of a research project, or who are effected by it (Saunders 2003:488). Any individuals or groups of people who become involved in the study or might be affected by it should be treated with due care (Saunders 2003: 129). Scrupulous attention should be paid to certain areas of the research. When collecting data researchers should: respect the rights and dignity of those participating in the research project, avoid harming their participants in any way as a result of the research, operate with honesty and integrity (Denscombe 2007: 141). Informed consent is a key element to ethically

sound research. It can be defined as: The position achieved when intended participants are fully informed about the nature, purpose and use of research to be undertaken and their role within it, and where their consent to participate, if provided, is freely given (Saunders 2003:479). In order to collate data for this study, the semi-structured interview was one of the research methods utilised. Informed consent was gained from all interview participants. Potential interviewees were provided with an introduction to the study, which described the research, its purpose and final use, before they agreed to participate (see Appendix 5). Participants, who were not formally interviewed, but played a role through informal discussions or in other ways, were made aware of the study and the purpose of the conversation. Interviews were over the telephone held at a time convenient to the interviewee. All were held over the telephone. At the beginning of the interview an overview of the study was given, and the purpose and final use of the data was reiterated. The last opportunity for withdrawal from the process occurred when participants were contacted to give final approval to text from their interview being quoted within the thesis. At this time, participants could either withdraw or alter their comments.

A list of questions was formulated, and these questions were targeted at appropriate participants. Interviewees were ensured anonymity, through pseudonyms, and confidentiality was guaranteed. Informed consent was obtained throughout the process. Privacy was also ensured through the use of coded transcripts. Interviewees were able to view their transcript to make alterations. Ethical approval for the research was granted on 14th July 2010, for the period July 2010 to July 2011, by Hannah Fairrimond, Chair of School Ethics Committee (see Appendix 4).

#### 6.9 Techniques and Quality Indicators employed for online and interview data.

The techniques that I employed for selecting, coding and analysing both the website blog and interview data were similar and relied more on a commonsense reduction and display of information than a complex system of codification. This is because both data arose out of research that was very flexible in design. For



website data I searched by theme and closely read each blog for 1) repetition of specific words, phrases and general thought patterns; and 2) topics that dominated the blogs as well as topics that were avoided. I then gradually reduced these data to a small set of generalisations that covered and gave voice to any key issues that I found in the data. I scrutinised all narrative about multiple births, multiple embryo transfers and single embryo transfer. All statements regarding an individual's experience with any of these topics were read carefully. I took extra care to analyse all expressions of emotion connected to any individual experience. As an IVF patient I felt that I was qualified to be an enquirer and listener with general sensitivity and my experiences in the IVF clinic had exposed me to look for contradictory evidence. I believe that the extracts that I took from the online blogs accurately represent the views of the people that expressed their opinions online. This was a similar process for the interview data obtained from counsellors. However, here the themes were broader and therefore I created a larger number of Microsoft files thematically and my resulting generalisations were larger in quantity. I made an effort to work with all of the relevant data, which was a challenge because it was so large. From this I gathered data under the 4 themes of counsellor, patient and clinic centred issues and multiple births. Again, as an IVF patient I was able to visualise and had personal experience of many of the items of discussion with counsellors. I felt that the time I had spent as a patient of an IVF clinic helped me to accurately interpret the experiences and opinions resulting from the experiences of the infertility counsellors.

The trustworthiness of the type of flexible qualitative research undertaken in my investigation is the subject of debate. Identical circumstances cannot be recreated to replicate the research. For example, my qualitative interview data consist wholly of participant's self-reflections. The small number of participants and purposeful nature of selection limits generalisability. However, I feel that neither limitations have influenced the relevance towards the ultimate goal of policy analysis. This study recognises the counsellors in their capacity as expert informers regarding the counselling provision in the clinics in which they work, and their own experiences and perspectives about the counselling sessions that they conduct. As I have previously mentioned, I felt that the counsellors I spoke to did represent the

counselling population in the United Kingdom as a whole. This is because I found counsellors from a variety of regions and from a range of work environments. Every region, variation of patient base and size of clinic was represented.

Some researchers using similar qualitative flexible designs deny the relevance of canons of scientific enquiry (Guba and Lincoln 1989). Others go further and reject the notion of any evaluative criteria such as reliability and validity (Wolcott 1994). These terms are avoided by Lincoln and Guba (1985: 294-301). They prefer the terms credibility, transferability, dependability and confirmability. By focusing on the credibility of my research I was led to a consideration of what constitutes good quality research, and any threats to its validity. Firstly the data collected had to be recorded at a point close to collection to ensure accuracy. In the case of my background research, this meant taking field notes either in the field or right after leaving it. For interviews with counsellors I used a digital recorder and for my Internet analysis I took postings straight from the Internet forums and pasted them in Microsoft Word folders. I then interpreted these findings thematically through note taking and looked for consistencies in data. I kept all the audio and written files on my home computer. I then needed to consider the bias that I, the researcher bring to this data. I feel that there is a low reactivity in my research as my presence was unlikely to change any behaviour from respondents in any of the research situations. There may be reflectivity in the research process (Crotty 1998). Here I as an individual had an impact on the research process. I felt that SET was a positive technique and important for IVF right from the beginning of the research because of my experiences in the IVF clinic. Therefore it is very important that my research is transparent in adopting this presumption. The close relationship between myself and the IVF setting and the respondents associated with this setting who were instrumental to my data gathering exaggerated this potential for bias. I feel that I stated my position of bias from the outset of the investigation. For further credibility of my research I checked my counsellor interview transcripts by returning them to the interviewees. I felt that this was an additional guard against researcher bias. I conducted a negative case analysis and did not find any pertaining to SET except that it may not be suitable for women in an older age bracket (Lawlor & Nelson 2012). I did find some negative cases

pertaining to the value of the counselling service in the clinic (Eijkeman 2009, Boivin 2011), here I took extra care to explore and dissect the research.

## **CHAPTER SEVEN –FINDINGS: SUPPORT SERVICES PROVIDED IN UK CLINICS**

**The next section of this investigation looks at patient support in the UK for those undergoing IVF. Patient support may assist a clinic's strategy for reducing multiple births. Patient support could be an important tool to promote SET. Different types of support such as counselling may provide a forum to discuss and inform a patient the benefits of a single pregnancy. Support mechanisms available through the IVF clinic may also help maximise the chances of successful implantation of the single embryo and therefore negating the perceived necessity of implanting multiple embryos. Chapter six of this investigation reviews the current literature in this area and it can be broken into two parts: The psychological Impact of infertility and psychological interventions. While many couples who seek treatment have high levels of psychological stress associated with infertility, the process of IVF itself is also associated with increased levels of stress. In the light of data suggesting that psychological symptoms may interfere with fertility, the success of infertility treatment, and the ability to tolerate ongoing treatment some interventions designed to alleviate the symptoms of stress, depression and anxiety in infertile women and men have here been researched.**

### **7.1.1 An analysis of support services available to patients in UK clinics**

I contacted all 86 fertility clinics in the United Kingdom to discover the level of support services offered in each clinic. My aim was to assess each clinic for the level of patient support and then look at the clinic's latest published success rates for IVF along with the latest published single birth rate. I wished to identify any trends in the level of support in the clinics and the success rate of the clinic. These relationships may indicate that stress reductive support may be one factor in increasing the success of IVF and hence helping a clinic to move towards the national goal of SET. The current single birth rate percentage is one indicator of a clinic's current commitment to reducing multiple births. Previously a study has

shown that competition among clinics does not appear to have any influence on rates of multiple births from IVF by promoting more aggressive embryo transfer decisions. In this study competitors were other clinics judged to be within a 20-mile radius. However, competition was strongly associated with patient mix. The proportion of cycles for patients under 35 years old was 6.4 percentage points lower for clinics with more than 15 competitors than for those with no competitors (Henne & Bundorf 2010). This study shows that the geographical position in terms of density of clinics should not influence any clinic multiple birth rate, even though those clinics in areas where there are many other clinics may have a broader mix in terms of patients.

The feedback to the HFEA regarding their staged SET policy is outlined in chapter three. It suggests that patients are more likely to adopt SET when staff at the clinic gives information about multiple births and SET from the very beginning of their treatment. All staff at the clinic need to give face-to face consistent information and it was found that two thirds of patients sought more information and discussion about SET through support systems surrounding the clinic, for example on-line forums and support groups (HFEA 2009). The provision of support services at a clinic allows for patients to explore their choices and get more information about SET.

All clinics are required by HFEA regulation to offer implications counselling to patients. Implication counselling explores both personal and family implications of infertility and consequent treatment. Generally such counselling takes place prior to the commencement of any treatment or whenever a significant change of treatment is contemplated so as to allow for significant reflection before making an irrevocable decision. However, it may also occur after treatment when acknowledging the reality rather than the possibility of an ART conception (Blyth 2012). Implication counselling ensures that each patient understands exactly what the fertility treatment that they are considering pursuing involves. This is especially important if their treatment is to involve donor eggs or sperm. Clinics may in addition offer support counselling. This aims to give emotional support at particular times of stress during the treatment and can help a patient to work through their

emotions. Some clinics may also offer therapeutic counselling. This focuses on mediating the more pervasive upsetting and stressful consequences of both impaired fertility and fertility treatment (Blyth 2012). Therapeutic counselling helps with the impact that infertility is having upon the patient's life and upon their relationships with others. It aims to help people cope with the consequences of their infertility and its treatment and is a forum to discuss patients' feelings. It includes helping people to adjust their expectations and accept their situation. Infertility is a medical condition that can be accompanied by a stress condition and patients will vary considerably in their emotional response to the condition and their ability to cope with it. Counselling tends to be shorter term than more in-depth psychological help and is a forum to discuss feelings associated with treatment. Clinics in the UK differ widely in the amount of counselling available and whether it is on or off site. The infertility counsellors that I interviewed (see later in this chapter) told me that some clinics offer counselling for free before during and after the IVF treatment for as many sessions as a patient requires. Other clinics with give between one and three free sessions and then patients are required to pay. Some of the clinics that they worked from require the patient to pay for all sessions. I contacted many counsellors at clinics and it was generally thought that there was a much lower uptake of counselling when the patient was required to pay. This is because of the financial strain involved in the IVF treatment itself. Additional costs were mostly avoided. Counsellors were keen to promote the value of free provision of counselling but many clinics were charging or limiting sessions because of financial cutbacks.

It is apparent that despite public policy that oversees the provision of infertility counselling, in the UK clinics vary widely in the type of provision of counselling they offer as well as in the other forms of support services they offer. The other services included: support groups, small topic-specific support groups (such as secondary infertility), on-line forums, clinic open days/evenings, bulletin boards, information about treatments in a variety of languages, coffee mornings/evenings, guest speakers, acupuncture, hypnotherapy, relaxation classes, yoga, breathing and meditation classes, mind/body courses, genetic counselling, early pregnancy counselling, miscarriage counselling, dedicated email for support, dietary and other

health advice and support, spa type environments, art, patient interactive websites, extra support from fertility nurses and preconception care with fertility coaching. I had to be certain to confirm that the fertility services that I investigated were offered during the period of my success rate data enquiry.

Not all of the 86 clinics in the UK were relevant to my enquiry. Many clinics did not offer IVF. They focused on less invasive fertility treatments such as IUI. Some clinics were very new and were therefore unable to display data pertaining to their success rates in 2008. Some clinics were very small and saw very few patients during the year that I looked at success rates (2008) hence the sample of patients was too small for data pertaining to clear unbiased success rates. To measure success rates for current data (2008) published in January 2010 I looked at live birth data. There was a patient breakdown for rates by age and I focused on fresh embryo transfer in women under 35 years of age as this category represented a higher proportion of patients (40.95%). Live birth data are gathered for HFEA records in 2 categories: live births per treatment cycle and live births per embryo transferred. I chose to focus on live births per embryo transferred because these data take into account how many embryos clinics transfer in any one cycle. Live births per cycle started, does not take into account that some cycles are cancelled before the transfer stage. During the data collection period the average live birth per embryo transferred in fresh embryo transfers for women under 35 years of age in any UK IVF clinic was 19.9%. I found it to be common and even usual, for fertility clinics to report success rates on their individual websites that were much higher than those recorded by the HFEA.

I also collected information about what percentage of births were single as this is relevant to my larger project of investigating multiple births during IVF and the implementation of SET. During the data collection period the average proportion of single births in any UK IVF clinic was 71.5%. I contacted each clinic relevant to my investigation by email, telephone and sometimes mail. I communicated with nurses, administration staff and many counsellors. The counsellors in clinics were very interested in my research as many felt that despite increasing clinical directives about multiple pregnancy and its reduction there was little attention given

to counselling directives on this issue and that it was a topic that frequently came up during counselling sessions with IVF patients.

Following is a list of fertility clinics in the UK and a map showing their location.



Table Two: List of UK Clinics

# Clinics licensed by the HFEA

(as at 1 March 2007)

For more information about each of these clinics, including the range of services they provide, whether they treat NHS or fee-paying patients and contact details, please go to the Find A Clinic section of our website: [www.hfea.gov.uk/ForPatients](http://www.hfea.gov.uk/ForPatients)

## Scotland

- 1 Aberdeen Fertility Centre
- 2 Ninewells Hospital, Dundee
- 3 Lanarkshire Acute Hospital NHS Trust, Airdrie
- 4 Edinburgh Assisted Conception Unit
- 5 Glasgow Nuffield Hospital
- 6 Glasgow Royal Infirmary
- 64 Glasgow Centre for Reproductive Medicine

## England (by region)

### North East

- 7 Newcastle Fertility Centre at Life
- 8 Centre for Assisted Reproduction, Gateshead
- 9 Sunderland Fertility Centre
- 10 Hartlepool General Hospital
- 11 Bishop Auckland General Hospital
- 12 London Women's Clinic, Darlington
- 13 Cleveland Gynaecology and Fertility Centre, Middlesbrough
- 14 The James Cook University Hospital, Middlesbrough

### North West

- 15 St Mary's Hospital, Manchester
- 16 CARE Manchester
- 17 Manchester Fertility Services
- 18 Hewitt Centre for Reproductive Medicine, Liverpool Women's Hospital

### Yorkshire and the Humber

- 19 ACU Leeds
- 20 Clarendon Wing, Leeds General Infirmary
- 21 Hull MF Unit
- 22 CARE Sheffield
- 23 Centre for Reproductive Medicine, Sheffield

### East Midlands

- 24 Queens Medical Centre Fertility Unit, Nottingham
- 25 NURTURE, Nottingham
- 26 CARE Nottingham
- 27 Derby City General Hospital
- 28 Leicester Fertility Centre
- 29 CARE Northampton

### West Midlands

- 30 Burton Hospitals NHS Trust, Burton upon Trent
- 31 Shropshire and Mid Wales Fertility Centre, Shrewsbury
- 32 St Jude's Women's Hospital, Wolverhampton
- 33 BMI Priory Hospital, Birmingham
- 34 Midland Fertility Services, Aldridge
- 35 Edtingham Women's Hospital
- 36 Centre for Reproductive Medicine, Coventry

### East

- 37 The Fertility Unit, Peterborough District Hospital
- 38 The Rosie Hospital, Cambridge
- 39 Bourn Hall Clinic, Cambridge
- 40 Isis Fertility Centre, Colchester
- 41 Brentwood Fertility Centre
- 42 Essex Fertility Centre, Buckhurst Hill

### Greater London

- 43 London Female and Male Fertility Centre, Highgate
- 44 Homerton University Hospital, Haringey
- 45 CFIM London, Marylebone
- 46 Reproductive Medicine Unit, UCL Hospital NHS Trust, Holborn
- 47 North East London Fertility Services, Ilford
- 48 UCH London, Camden
- 49 MF Hammersmith, Acton
- 50 Assisted Reproduction and Gynaecology Centre, Marylebone
- 51 The Centre for Reproductive Medicine, Barts and the London
- 53 The Lister Fertility Clinic, Chelsea
- 54 London Women's Clinic, Marylebone
- 55 The Harley Street Fertility Centre, Marylebone
- 56 Cromwell MF and Fertility Centre, Chelsea
- 57 London Fertility Centre, Marylebone
- 58 Chelsea and Westminster Hospital, Fulham
- 59 The Bridge Centre, London Bridge
- 60 Guy's Hospital, Waterloo

### Greater London (cont)

- 61 ACU King's College Hospital, Camberwell
- 62 Queen Mary's Hospital, Sidcup
- 63 Shirley Oaks Hospital, Croydon
- 64 BMI Chesham Park ACU, Orpington

### South East

- 65 Oxford Fertility Unit
- 66 BMI The Children's Hospital Fertility Services Unit, Great Missenden
- 67 The Woking Nuffield Hospital
- 68 BMI The Chaucer Hospital, Canterbury
- 70 Wessex Fertility Limited, Southampton
- 71 The Princess Anne Hospital Fertility Unit, Southampton
- 72 BMI The Experience Hospital, Sussex Downs Fertility Centre
- 85 South East Fertility Unit, Tunbridge Wells
- 86 The Agora Gynaecology and Fertility Centre

### South West

- 73 Southmead Hospital, Bristol
- 74 Centre for Reproductive Medicine, University of Bristol
- 75 Bath Assisted Conception Clinic
- 76 Salisbury Fertility Centre
- 77 Peninsula Centre for Reproductive Medicine, Exeter
- 78 BMI The Winterbourne Hospital, Dorchester
- 79 South West Centre for Reproductive Medicine, Plymouth

## Wales

- 80 London Women's Clinic, Swansea
- 81 Cardiff Assisted Reproduction Unit

## Northern Ireland

- 82 Regional Fertility Centre, Belfast
- 83 Origin Fertility Care, Belfast

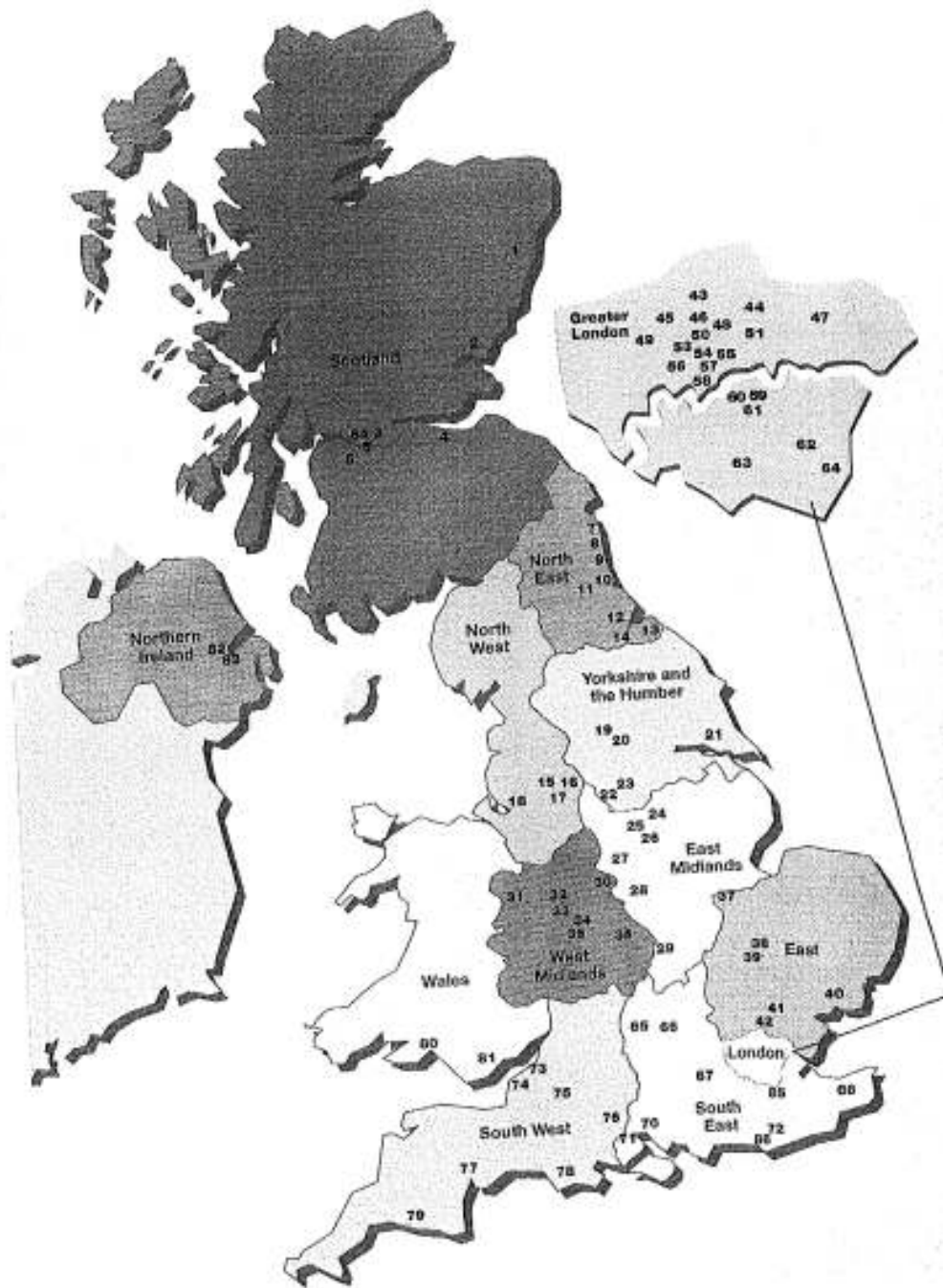


Table Three: Map of IVF Clinic location

### 7.1.2 Summary of my findings by area

#### EAST MIDLANDS

The East Midlands had 4 clinics relevant to my investigation. Three of the four clinics had much higher than average success rates. One clinic had the second highest success rate in the UK with a birth rate per embryo transferred of 29.7%. The proportion of single births was also much higher than average at 76.6%. This clinic was owned by Nottingham University and all profits from the clinic were channelled back into the university to support research and education. Support Services were easily available to patients with counselling sessions offered to all patients during, before and after treatment. Sessions are free and patients may use as many sessions as they like. The clinic has a clear easy to navigate website with a patient support group attached to the website. The counsellor at the clinic suggested that more and more patients are using the online forum as an alternative to the informal face-to-face patient support also offered. The waiting room and other rooms in the clinic are clearly thoughtfully designed to provide a comfortable and relaxing atmosphere. While support services are readily available this facility also prides itself upon technical advancement- they possess advanced imaging and molecular biology equipment. Their £1 million research facility focuses on the causes of infertility and the development of improved methods for assisted reproduction. Patients are asked to consider taking part in research. This would for example, involve researching control of the ovary, growth of eggs and subsequent embryo development and implantation. The facility has a 3D colour doppler ultrasound machine which is able to monitor blood flow and volume enabling an in depth analysis of the womb and how blood flow affects the ability to conceive which can predict responses to treatment and other abnormalities in the womb effecting conception. The latest investment from the university for refurbishment has been £100 000 on a ventilation system which prevents embryos being exposed to impurities in the air which could cause them to die or compromise their ability to develop properly.

Of the other 3 clinics in the East Midlands, 2 other clinics had higher than average success rates with 24% and 26.4%. Single birth rates were below average in both clinics 62.3 and 68.4. Both clinics show high levels of support but the clinic with the lower success rate charged for counselling after 3 sessions. Support groups were available at both of these clinics. The other clinic showed similar levels of support but lower than average success rates (16.8%) and low single rates (67.5%).

## EAST ENGLAND

Four clinics were investigated in this region. Other clinics were new without success rate data or didn't offer IVF. Two clinics, which were managed jointly, enjoyed higher than average success rates 20.6% and 22.6%. Single births were also higher than average at 74.5% and 80%. The clinic without the very high single birth rate transferred a high percentage of blastocyst stage embryos - and it is thought that the blastocyst stage embryo allows the embryologist more information when deciding which embryo to return to a patient. The other two clinics showed lower than average success rates 16.2% and 17.7% and lower than average single births 62.5% and 72.1%. The 2 clinics with higher success rates showed elevated support with all counselling free to patients at all stages of the treatment. There were information sessions in the day and evening, patient support groups and speakers of other languages were accommodated. The other two clinics with lower rates showed average support services. The 2 more successful clinics had been in business many more years and were pioneers in IVF treatment. None of the 4 clinics conducted research or had links to teaching hospitals or universities.

## SCOTLAND

In Scotland 6 clinics were relevant to my investigation. Three clinics had much higher than average success rates: 23.6%, 24.6% and 24.5%. All three clinics showed lower than average single birth rates: 65.2%, 71.4% and 68.1% All three clinics provide free counselling before, during and after the IVF treatment. All three clinics run in collaboration with medical research at major universities in the area

and patients are asked to participate in research. The three clinics with lower success rates 19.9%, 15.1% and 19.5% showed an average provision of counselling services and were not attached to any university research department.

#### WALES, NORTH EAST ENGLAND, NORTHERN IRELAND

These areas in the UK did not have a proliferation of IVF clinics. Wales had 2 clinics both with an average provision of support services and low success rates: 15.7% and 17.6%. North Eastern England had 2 clinics with average support and slightly lower than average success rates: 18.2% and 19.2%. Northern Ireland also had 2 clinics both of which offered counselling and plenty of treatment in other languages. The clinic's success rates were lower than average at 12.5% and 17.5%. The clinic with the higher rate offered all counselling for free. None of the clinics offering IVF in these 3 areas were attached to universities or teaching hospitals.

#### LONDON

Of the eleven clinics providing IVF services and established long enough to display current success rate data 8 clinics showed higher than average success rates for 2008. One clinic stood out as having the highest success rate in the UK during that year at 30.8%. This clinic had a sister clinic in the South East which also demonstrated very high success rates (27%) and operated on the same principles. The clinic boasted a holistic approach, whereby the patient was empowered with knowledge and information. All counselling is free before, during and after IVF services. The single birth percentage rate was very high at this clinic at 78.1%. Although the clinic was not directly connected with any one university it had carried out and published research which looked at the success rates involved with transferring a single blastocyst (later stage embryo) and 2 blastocysts in 2 different samples of age group patients 25-37 years and 38-43 years. They concluded that single blastocyst transfer had a more successful cumulative birth rate and a lower multiple rate in the younger age cohort but that 2 blastocysts were desirable for the older patients because the cumulative birth rate was considerably lower without the

transfer of just one blastocyst and the chances for pregnancy were low (Abdalla 2008). In terms of the order of success rate, the clinic in London with the second highest rate: 26.3% was progressive in terms of patient support and promoted acupuncture as a stress management tool alongside counselling. The clinic is attached to University College Hospital and collaborates with the genetics team at University College, London. Technological innovation is important to the clinic and vitrification (rapid freezing) of oocytes is promoted and is thought to offer better post thawing survival. The clinic is also unique in providing an Ovarian Stimulation Test, which helps to plan a tailored drug protocol for all IVF patients. Despite high success rates this clinic offered low single birth rates at 64.9%. The clinic with the third highest success rates 25.5% operates with a spa type environment throughout the clinic and promotes purity of environment with a customised air handling system to protect embryos. Counselling is free to all patients before, during and after treatment and patients are encouraged to make informal visits for support to fertility nurse. Single birth rates at this clinic are high at 75.6%. Fourth highest success rates came from a clinic backed up by one of London's most prestigious teaching hospitals: Guy's and St. Thomas NHS Foundation Trust. The clinic has facilitated 20 years of free counselling to patients and it was reported that their patient support groups were well attended. Success rates for 2008 were 22.2% and single births were high at 75.7%. The other four clinics with higher than average success rates reported figures of 21%, 20.8%, 20.4% and 21.6% respectively. Recent research from Guys hospital has discovered that a woman undergoing a single embryo transfer is more than twice as likely to miscarry if she has a high Body Mass Index (Rittenburg 2011). This finding lends support to weight awareness support as part of a catalogue of support services. Another finding reported at ESHRE's 2011 annual meeting in Stockholm discovered that women with gum disease took on average two months longer to conceive. For non-Caucasian women this could extend to being as long as one year (Hart 2012).

In London, the clinic with the highest recorded success rate provided a mind/body course that aims to give patients the skills to reduce stress at every level of treatment. It is a ten-week program with hatha yoga, breathing and stress management - a 70% pregnancy rate is boasted for attendees. At this same clinic

various types of counselling are offered as well as a recurrent miscarriage support service. All services incur costs to the patient. The clinic with the next highest rates mandates an emphasis on the holistic care of patients with free access to counselling and widespread recognition of the emotional needs of patients. I was told that 350 patients attend 1000 counselling sessions a year. This clinic also conducts research and has a quality management system (such systems are slowly being introduced to IVF clinics in the UK as a result of European regulations- April 2007 European Tissue Directive). The clinic demonstrating the third highest success rates in London offers patients 2 free sessions of supportive counselling during IVF treatment. Therapeutic counselling needs to be paid for at £450 for 6 sessions and there is a £100 fee for implications counselling. The last clinic of these four charges for all counselling after a free introductory session. Fertility coaching and pre-conception care is provided. Single birth rates were not higher than average in any of these four clinics. The three clinics with lower success rates in London- 17.2%, 17.5% and 14.4% all provided average levels of support mostly just counselling some of which was free. None of the three clinics displayed higher than average single birth rates.

#### NORTH WEST ENGLAND

There were four clinics in this region that had information relevant to my investigation. Three were in Manchester. Two clinics had higher than average success rates 20.1% and 21% and higher than average single birth rates: 76.1% and 76.9% respectively. The first of these clinics was the largest NHS provider of IVF services in the UK. Free counselling is offered before, during and after treatment. The clinic has a well-attended support group that meet to chat and discuss their treatment experiences. The group also listens to guest speakers, who are frequently scheduled to give talks on infertility topics. The counselling department publishes a frequent newsletter and has conducted research about levels of stress during the 2-week waiting period for a pregnancy test for IVF patients. The other clinic in Manchester with higher than average success rates conducts much research in partnership with the University of Manchester and the

Central Manchester NHS Trust. This mostly focuses on embryo development and improvement of laboratory methods. Current research in conjunction with Manchester and York Universities focuses on techniques to implement single embryo transfer by looking at new methods of embryo selection to identify biochemical markers of the best embryos to be replaced. Counselling at this clinic is free for the first two sessions and thereafter charged at a rate of £50 hourly. Appointments with fertility nurses can be made free of charge for ongoing support. The other clinic in the area displayed success rates of 17.9%. Their single birth rate figures were 69.4%. This first clinic offered an average level of support services.

## SOUTH EAST ENGLAND

Of the 8 clinics in the South East of England offering IVF and publishing success rates 5 clinics offer higher success rates and elevated levels of support services. One clinic had slightly lower than average success rates and 2 clinics were much smaller which is likely to influence success rate data so I haven't included them for summary findings. One clinic had the 3rd highest success rates in the country 27% and a very high single birth rate of 87.9%. Counselling is offered to all patients for free before, during and after treatment. The clinic forms part of a chain of hospitals, 2 sister fertility clinics, one in the South West of England and another also in the South East of England also boast very high success rates and single birth rates. The second clinic I contacted had a high success rate 25.5% and very high single birth rate 91.7%. This clinic has a very successful sister clinic in London that boasts the highest success rates in the country for the recording period. In the London clinic counselling is free but at this clinic the charge is £55 per session. An identical spa-type environment is offered in line with the London clinic and they have the same advanced air handling system to protect fragile embryos. A quality management system is also in place in accordance with the April 2007 European Tissue directive. The support group appears to be well managed and well attended. The 3rd clinic approached had good success rates of 25.6% but low single birth rates of 62.3%. All types of counselling are free for as many sessions as required and it is part of a chain of hospitals with other fertility



clinics in the UK. Counselling policy is constant throughout the other fertility clinics. The 4th clinic had a success rate of 23.5% and a single birth rate of 75.6%. Support groups are highly emphasised at this clinic, meeting regularly with guest speakers. Smaller support groups to provide support in specific areas are organised to suit patient needs. The 5th (21.3% success rate and 73.5% single birth rate) works in partnership with leading researchers at the University of Oxford and has an international reputation for research. An example of research would be an investigation of implantation to find out how the embryo attaches, invades and interacts with the different cell populations of the endometrium and why IVF fails. The unit has a sophisticated counselling service and also employs a psychologist. The first session is free for patients and then there is a charge. A counsellor informed me that 17.5% of patients use the counselling service. The clinic with slightly lower than average success 19.1% and a single birth rate of 67.6% offers 3 free counselling sessions with more arranged on request. They have a weekly coffee morning to offer support but uptake is limited.

## SOUTH WEST ENGLAND

Many clinics in the South West of England were too small to give reliable success rates or did not offer IVF. Five clinics offering services and publishing results were in bigger centres: Bath, Bristol, Exeter, Plymouth and Bournemouth. Four clinics offered higher than average success rates. The highest success rate was 25.9% with a single birth rate of 79.3% this clinic is part of a chain of hospitals with other successful fertility clinics in the UK. Counselling services are free and available at all levels of treatment. The second clinic offered a success rate of 22% and a single birth rate of 71.4%- the counselling services at this clinic is also free to all patients. The other two clinics in the South West display success rates of 20.8% and 17.6%. Single birth rates for these clinics are 71.1% and 73.3%. Both clinics offer free counselling. Generally speaking in the South West support services other than counselling were not prolific. One clinic had an in-house and on-line support group as well as a healthy eating program and this was a larger clinic in a larger city.

## WEST MIDLANDS

In the West Midlands 6 clinics offered data relevant to my research. Only one clinic reported higher than average success rates with 20.3%. The clinic's single birth rate was very low at 59.1%. This unit offered 3 counselling sessions free and then charged patients for further sessions. The other 5 clinics reported low success rates: 17.4%, 13.3%, 16.3%, 19.1% and 18.2%. All clinics in the West Midlands offered counselling and patient support in the units. It appears that overall the clinics are patient focused. Like success rates single birth rates are also average to low: 72.9%, 67.9%, 59.1%, 75.4%, 64.8% and 68.4%.

## YORKSHIRE AND HUMBER

Four clinics were contacted in this region. Two clinics stood out as having slightly higher than average success rates than other clinics in the region. The first had a reported success rate of 20.6%. This clinic demonstrated very high single birth rates at 82.8%. Counselling at this clinic is free to all patients at every level of treatment. The clinic is a pioneer in low dose FSH fertility drug treatment and tailors drug plans for each patient. The second clinic showed success rates of 20.4% and a single birth rate of 72%. This clinic had counselling freely available at all levels of treatments and counsellors were required to be educated to a minimum of an MA standard. The clinic did much research in association with the University of Hull and Hull-York Medical School. It has produced over 66 publications in the last 10 years. The largest research project has been into the cause of ectopic pregnancy after IVF as a result of uterine contractions. Clinics with slightly lower than average success showed rates of 18.8% and 19.2% respectively. Single birth rates at these clinics were both 71.1%. All counselling was free at all levels of treatment at both clinics. The first clinic offered both a face-to-face support group and an Internet chat room for support. The clinic suggested that more patients used the chat room than counselling or the other support group. The other clinic offered an on-line support group in the form of a bulletin board that was heavily used by patients and a fitness management course.

### 7.1.3 Summary of UK IVF Support Provision

The investigation showed that the South East of England and London had a large proportion of IVF clinics that were generally progressive in offering high levels of support to their patients. Success rates were high in these clinics, as were single birth rates. The East Midlands and Scotland had a large proportion of their clinics also offering good levels of patient support and high success rates and high single births rates. These clinics were all associated with research departments at major universities. Clinics in Wales, Northern Ireland and the North East of England all showed average to poor support levels and average to poor success rates. Elsewhere in the UK: East England, South West England, West Midlands, North West England and Yorkshire and Humber support levels were average as were success rates. There were a few clinics that stood out as having slightly higher than average success rates in these areas and all of these clinics had elevated support services.

My enquiries confirm that despite comprehensive health policy to oversee the provision of counselling in IVF clinics in the UK, on an individual level the actual provision of these service and other supporting services is widely variable across the country. The statutory requirement for all UK, IVF clinics to offer the service to patients is not being routinely endorsed by all clinics and there is a variable interpretation of the law. Current regulations may be manipulated according to the mandate of each clinic. This leaves room for reforms. In order to investigate counselling and other support provisions further and clarify how they may relate to SET provision I contacted counsellors themselves to gain their insights. This work is detailed in the rest of this chapter.

### **7.2 Interviews with IVF Counsellors**

For this part of my investigation I conducted qualitative interviews with counsellors who support patients before, during and after the IVF process. This investigation seeks to discover how public policy regarding the provision of patient support in the form of counselling is implemented in fertility clinics offering IVF. Policy regarding

patient counselling has been issued by the HFEA. The 1990 Human Fertilisation and Embryology Act mandate is that counselling be offered to a fertility patient and any intended second parent. The counselling should inform parties about the implications of the treatment. The HFEA has interpreted the law and given policy directives for each clinic to comply with. Failure to comply with this directive could result in revocation of a clinic's licence. The policy is stated in the HFEA's 8<sup>th</sup> code of practice. The policy states that each clinic should take practicable steps to provide an opportunity for counselling before, throughout treatment and afterwards. The implications for a patient for both donating materials and receiving donated materials should be given separately from other implications counselling. Currently, in the UK most counsellors are accredited by BICA. The investigation assessed the level and form of implementation of policy with regard to counselling in the sample of clinics. The project aims to assess some patient attitudes about multiple pregnancy and birth, the subsequent effect that counselling may have upon these feelings and whether or not counselling is part of or could be part of any clinics' response to the HFEA mandate to reduce the multiple birth rate.

### 7.2.1 Discourses of Counselling: the Counsellor's Perspective

#### Synopsis

My interest in counselling provision follows my research question. I propose that counselling may be a forum to more fully discuss SET as a treatment option with the patient. One policy response to the problem of multiple births and IVF could be, increasing support and discussion forums in the IVF clinic. This may be done by through the existing counselling framework that is mandatorily in existence in UK infertility clinics. The counselling service could offer a space for patients to explore SET. The counsellor could impart information about the SET procedure and allow for a full and informed discussion about the procedure within the framework of the clinic's SET policy. In this way a clinic may promote SET policy with full and informed consent by any patient intending to embark on the procedure. By interviewing counsellors I aimed to assess the current provision of counselling in the UK and explore ways in which current provision may be expanded

accommodate a comprehensive promotion of SET policy.

Some evidence also shows that the outcome of infertility treatment may be influenced by psychological factors. A number of studies have examined stress and mood state as predictors of outcome in IVF. The majority of these studies support the hypothesis that distress is associated with lower pregnancy rates among women pursuing infertility treatment (Boivin 1995, Demytenaere 1998, Sanders 1999, Smeenk 2001, Thiering 1993). In the UK support for fertility patients is a public policy issue. The government requires every clinic to offer a minimum level of counselling to certain types of patients. I wish to look at the types of support clinics in the UK are offering patients to decrease distress and see if support mechanisms are in any way incorporating government mandates to decrease the multiple birth rate at UK clinics.

At the start of the project, I specifically aimed to assess as a key part of the interviews, some of the counsellor's perceptions about patient attitudes about multiple pregnancy and birth, the subsequent effect that counselling may have upon these feelings and whether or government mandated provision of counselling is part of any clinics' response to the HFEA mandate to reduce the multiple birth rate. Feedback to the HFEA regarding their staged SET policy is described in Chapter 2. It suggests that patients are more likely to adopt SET when staff at the clinic gives face-to-face information about multiple births and SET from the very beginning of their treatment pathway. All staff at the clinic need to give consistent information and it was found that two thirds of patients sought more information and discussion about SET through support systems surrounding the clinic, for example on-line forums and support groups (HFEA 2009). Another study found that the longer term infertile patient displayed significantly more positive attitudes about the prospect of a multiple gestation than the newly infertile control group (Leiblum 1990). This study suggests that evidence relating to multiple pregnancy risks needs to be carefully organised around the individual needs of each patient. The counselling forum may provide an exclusive opportunity for such discussion. Previous research into counselling in the IVF clinic setting has suggested that patients find their experience of counselling to be positive and beneficial regardless

of whether it is voluntary (Stewart *et al.* 1992) or mandatory (Connolly *et al.* 1993).

Most counsellors were of the opinion that multiple birth mandates were successfully being taken care of by clinicians at their particular clinics. This is contradicted by data from the HFEA in 2012 that suggested most UK clinics struggled to achieve 15% multiple birth targets (see chapter 2). However because counsellors felt the clinicians were responsible for HFEA policy mandates my interviews became largely focused on other practical issues regarding the functioning of the particular counselling service at the clinic that the counsellor worked out of. The interviews became a study of the interplay between the provision of Government policy in the form of counselling, what is happening in counselling in clinical practice and in what ways and by whom counselling is perceived to be a form of important emotional support during the fertility treatment process. Despite HFEA regulation relating to counselling provision there were clearly large differences in the type of support provided between clinics. These differences related to the structure of the infertility 'industry' and the ways in which the services of each clinic were utilised by their clients. The discussion arising from interview material focused upon how services may be generally and uniformly improved for patients. If counselling services are uniformly improved in UK infertility clinics then it is possible that counsellors can provide a consistent forum to promote clinic SET policy. This could be endorsed by the HFEA in corroboration with existing multiple birth reduction policy. The list of interview questions can be found in appendix 6. The interviews are treated confidentially and no identifiers are included. All direct quotations in the following text are comments from the interviewees themselves.

### **7.3 Findings: Clinic Centred Issues**

**Following are discoveries I made from interviewing counsellors. This section details reoccurring issues that frequently arose relating to the mechanisms and resources of the IVF clinic itself.**

#### **7.3.1 Support Groups**

I found that only a very small minority of clinics ran a support group. Clinics more often provided online community forums, which are a heavily used support mechanism for patients. Counsellors suggested that clients had used web and chat rooms that were infertility focused but not associated with the clinic. I have made an investigation of these sites in the next chapter. Some counsellors indicated that online support had in many ways replaced traditional face-to-face support groups and have partly been responsible for the drop off in numbers of attendees to support groups over the years. Nearly all counsellors commented that they had more and more email contact with patients. Although this isn't technically counselling, I was told that this has become a valuable support service that addresses hefty issues that patients want to address, at particular times in the treatment cycle. All clinics also offer telephone counselling.

### 7.3.2 Leaflets and Notices

Other most commonly cited forms of support were in the form of leaflets or notices on a noticeboard in the waiting room. These leaflets may outline counselling services available at any particular clinic. They may also put patients in touch with voluntary or charitable organisations such as 'The Donor Conception Network'. Leaflets can also detail local private support such as reflexology or relaxation classes. Additionally there may be information available with reference to private health insurance. However, in these cases it is up to the patient to make contact with the mechanism of support and the clinic itself is not involved. Leaflets were thought to be of more value to a patient when actively promoted by a clinic staff member. Instead of saying "We've got a counsellor, there's a leaflet up there", it was thought to have made enormous difference when the staff positively discussed the service in question. For example "Why don't you try counselling, a lot of people find it really really helpful". Two of the counsellors I spoke with cited that patients had frequently complained to them that they "had wished they had known about their service". At these clinics there were leaflets sitting in the waiting rooms but none of the clinic staff talked about the counsellors. Another clinic was actively

recommending and promoting other forms of stress alleviation such as suggesting patients see an acupuncturist or reflexologist. To be successful, it is widely thought by the interviewees that the support service has to be personally endorsed by all clinic staff. The support mechanism, be it counselling or other support, needs to be embedded into the culture of the clinic. This may involve training all staff on all levels and some clinics ask the counsellor to have a training session with other staff members to do this.

### 7.3.3 Open –evenings

Lastly, most clinics run open evenings once a month or more. These evenings invite prospective patients to hear about what services are provided and how they are provided. Members of the team such as the counsellor or embryologist are invited to talk. Attendees get to look around the clinic and familiarise themselves with staff. These sessions serve as information giving rather than support. They do however often provide opportunity to see the clinic counsellor and hear about what counselling may offer in the context of fertility treatment.

### 7.3.4 Patient Users

Interviewees had difficulty quantifying the exact percentage of patients who use counselling. Sometimes this was because clinics keep treatment cycle data and not patient number data. This makes it difficult for counsellors to keep accurate records. A few counsellors simply stated that they “did not know who they weren't seeing”. Two counsellors suggested that they felt about 15% of patients have some contact with counsellors. The counsellor of one clinic told me that:

“ 15% of clients have some contact with a counsellor”

(UK infertility counsellor)

This fairly low figure was despite the fact that the clinic where she worked had good counselling provision and unlimited offered counselling before, during and



after treatment. She described how one parent of triplets used the service 13 years after treatment. She considered this an appropriate use of the counselling service. Despite the fairly low uptake she told me that:

“90% of patients are aware of the service”

(infertility counsellor)

Other counsellors gave a rough estimate of 30-40% uptake of counselling at the clinics where they worked. Many other larger clinics supported the 30-40% estimate. Other estimates seemed dependent on the type of services the clinic offered and whether clinic policy deemed counselling mandatory for such services. A clinic that did keep counselling audit statistics felt that they had a "high take-up of 30% of patients" using the counselling service. One survey at the clinic showed that over 92% of patients are aware of the existence of counselling as a service that is offered within the fertility clinic. One counsellor explained that it was very hard to get access to statistics unless they are very well integrated with the rest of the fertility clinic team.

I was advised that there is a certain sector of the patient population for whom most clinic policy required counselling to be mandatory. These include those people in surrogacy arrangements and social egg freezing (where a patient intends to freeze their eggs for non medical reasons). The majority of counsellors told me that the clinics they work in, insist that patients go to counselling where there is a use of any donor gametes. Many donor arrangements involve complicated familial arrangements. For example, if a sister donates an egg to a sister the resulting child would be both cousin and sibling to any existing children of the donor. This type of mandatory counselling is very often referred to as implications counselling (discussed later in this chapter). A small minority of counsellors (working at exclusively private clinics) said that they felt most donor treatment had now become more mainstream, understood and out of the 'public view'. Therefore those particular clinics no longer felt counselling should be compulsory in all donor

circumstances. It was felt that the newer treatments needed mandatory referral to the counsellor and which ones demanded this attention depended upon scientific progress.

The counsellors I interviewed estimated that between 60 and 99% of their work fell into the implications counselling category. For each particular clinic the percentage of referrals for implications counselling verses support counselling will be dependent upon the range of programmes any clinic is licensed for. Those offering complex treatment such as egg sharing will reflect these policies in their client counselling group. The culture of the clinic may also be reflected in such estimates. Clinics, which promote counselling, may have a higher percentage of counselling clients coming for general support and therapeutic sessions. These clinics are larger and offer unlimited free counselling, they may be private exclusively or NHS mix. However all clinics which did not promote counselling or whose services were limited and costly to patients were exclusively private clinics and usually smaller in size.

All counsellors cited instances of where a clinician felt that there was an issue during the treatment and this resulted in them saying something like, "We won't go further unless you see a counsellor". All of the counsellors that I interviewed felt that a very low proportion of patients were actively seeking counselling of their own accord. Patients would not say initially after accepting fertility treatment that they would like to see a counsellor. Clinic policy either makes it mandatory, or nurses, ultrasonographers, clinicians or other members of staff may suggest it.

One of the counsellors, who cited a low rate of take-up for counselling at 10-15% in the small private clinic where she worked, said that HFEA inspectors had made criticism of such low participation in the service. She felt that the reason for this was that the clinic was not interested in counselling and only had a counsellor because they need one in order to get a licence. They were not interested in putting a counsellor forward or the idea of counselling forward. In this clinic there was no encouragement from the clinic team for any patient to undertake

counselling. This particular clinic only saw patients for counselling when the fertility procedure involved donor material. Occasionally a patient would be referred who 'burst into tears' in front of a clinician. This was thought to be 'not coping' with the fertility treatment and at this point the counsellor became a 'necessary' resource to the fertility process. The counsellor "fought long and hard" for one session of counselling to be included in the cost of treatment. This took quite a long time to achieve but is still only given free for compulsory implications counselling, usually in cases of surrogacy. All counsellors I interviewed with the exception of one suggested to me that it is very hard to cover all implications and provide support for the patient in just one session that typically runs for about 50 minutes. The majority of counsellors said to me that they saw nearly all of their clients only once.

Six of the counsellors I interviewed told me that the clinics they are attached to offer unlimited free counselling services. There was always at least one counsellor available at the clinic during open hours and they were said to offer a completely "open door" service. A patient may see a counsellor whenever they wish to at any point before, during or after treatment. Patients are instructed to telephone the main medical secretary to schedule an appointment and all staff in the clinic work with an electronic calendar system. This was more common in larger clinics regardless of whether or not their patients were NHS or private self-funded. Clinics that required patients to pay for counselling or only offered very limited free counselling were all private clinics and were smaller clinics. This suggests that cost is an issue in the provision of counselling but only to a certain extent. When private clinics get bigger and expand they appear to more readily absorb the cost of counselling into their overall fertility service provision.

#### **7.4 Findings: Patient Centred Issues**

**The following findings describe the reoccurring themes that counsellors identified in their patients' reaction to and perceptions of the counselling service itself.**

#### 7.4.1 Counsellors' reports of IVF Patients' Perceptions of Counselling

The majority of counsellors thought that the biggest barrier for patients accessing counselling services were their perceptions and preconceptions of what counselling actually is. They felt that fertility patients have a negative perception of seeking this type of help. I was repeatedly told that “patients were quite resistant to counselling”. There is for many, a stigma attached to infertility itself. This is explored fully by Slade and associates (2007). Their study concluded that in preparation for infertility treatment, some discussion around the issues of stigma and disclosure might be helpful together with consideration of gender differences. Although there was a clear gender differentiation within the infertility counselling profession (all the counsellors I interviewed were female), I was told by all the counsellors that the offer of counselling was made to all parties involved in the IVF procedure.

“the invitation is always to the couple and we would never send an invitation to just one party”

(UK infertility counsellor).

For those requiring counselling, it may be that specific cognitions about stigma are common and could be targeted in therapeutic input (Slade *et al.* 2007). Many patients want as few people as possible to know that they are going through fertility treatment and are therefore hesitant to share something with people that they think should remain private and be maintained within their relationship. This can be translated as a heteronormative emphasis on the relationship between partners or spouses as the primary and privileged source of support in the engagement with treatment. This constrains both men and women from seeking formal support elsewhere. This is then amplified by the perceived stigma associated with counselling. This supports Throsby's research where she interviewed IVF patients in the UK in late 1990s through to 2003. Here she found that the gendered division of emotional support during treatment to be highly problematic and often ineffective

(Throsby 2003).

One counsellor that I interviewed told me that many of the patients at the clinic have no other problems in their lives apart from the fact that they are forced to seek medical help with conception because they have a medical problem, are in a non-heterosexual relationship or are single. This counsellor thought that those are not things that the general public would feel warrant a therapeutic need for professional support and this is how the general public view counselling.

“no other problems in their lives apart from the fact that they have a medical condition and this is not something the public perceive as a therapeutic need”

(Infertility counsellor)

However these situations and their effect on fertility may still lead to feelings of being overwhelmed, depressed, anxious and unable to cope with life. People do not want to be categorised as having problems. They might fear that they will be judged or misunderstood which can make it hard to open up but there is often a desperate need and desire to talk through difficult experiences and to have feelings heard and validated. Some counsellors cited their patients summarising this attitude by saying "We didn't use counselling before because we thought we didn't need it". However something will often come up either medically or there were changes in the couple's relationship that brought them to counselling. Another counsellor told me "It is my sense that in the UK the idea of seeing a counsellor is not consistent with being healthy". Clearly many people still view counselling as embarrassing or as a social stigma. They view counselling as being a service for those people who are 'weak' with mental health issues or 'can't manage' the fertility treatment. Counselling may even be seen as a punitive addition to the gruelling fertility treatment: "Other people conceive naturally and don't have to see a counsellor". My findings strongly reinforce Throsby's findings; she concludes that gendered social and reproductive norms can constrain those undergoing IVF, or coping with its outcomes, from seeking assistance and support through

counselling. She found that her subjects were not necessarily cynical about counselling as a resource but found that the experience of fertility treatment had undermined the interviewee's "sense of belonging" and the repudiation of counselling was one means to relocate the self in the public domain (Throsby 1993).

#### 7.4.2 Patients' Fear That Treatment May Be Withheld

Several counsellors commented that patients were concerned that if the clinician at the clinic hears that a particular patient has seen a counsellor, then that doctor will feel that they are "not good enough to have a baby". Counsellors told me that they observed a lot of fear when they examined patients' attitudes towards counselling and thought that fear is especially attached to the possibility that the counsellor may "unearth something, which might mean that I can't have treatment". There is a widespread concern amongst patients that they will be judged negatively by staff in the fertility clinic if they are in "need of this kind of support" and fear that this might inhibit the fertility treatment itself. Even though once in the room confidentiality issues are uniformly emphasised to every counselling client, there may be fears about conversations not being confidential which inhibit the seeking of treatment. Furthermore, very often just the thought of the clinic itself knowing that counselling has taken place is enough to raise concern.

There is a legal requirement in the Human Fertilisation and Embryology Act that the fertility team take into account the welfare of the child (HFE Act 2008). The counsellor's involvement in this was found to vary for different clinics. Some counsellors incorporate a level of assessment into their work and this involves a different confidentiality contract and is not counselling. Two counsellors involved in this type of assessment described a tension with a social work role and a therapist role when asked to operate in the context of child protection. The majority of counsellors I spoke to did not work in this context. However when working in a role where the legal 'welfare of the child principle' is paramount, counsellors are not entirely able to guarantee complete confidentiality and this itself may contribute to fear on the part of the patient that attending counselling may result in the

withdrawal of treatment.

#### 7.4.3 Patients' Fear That Uncovering Painful Feelings Will Affect Treatment Outcome

According to counsellors I interviewed many patients have a resistance to talking about painful issues because they perceived and believed that this would make them "weaker, rather than stronger and more positive". The clinic often enforces the notion or perspective that thinking positively will produce a baby and high infertility treatment failure rates are often not discussed. Counselling almost contradicts this because it is a painful process. Patients will often cry and issues of grieving and loss are explored. Being "upset" is not viewed in the minds of many infertility patients as being consistent with or conducive to being "positive" and focusing positively on the single goal of producing a baby. There is a fear amongst patients that a counsellor will introduce subjects and aspects of their lives that they don't want to talk about. Counsellors told me that it was not necessarily that patients don't want to 'talk' but there is a great fear about what it will entail. This fear is often gendered. The counsellors that I spoke to speculated that women are likely to conceal feelings in order to enable them to enrol upon and cope with the physically and emotionally challenging, vigorous steps of the treatment process. The counsellors thought that male partners would conceal feelings to adhere to a masculine image that is not consistent with being infertile. This was confirmed by Throsby in her research where she found an 'emotional script of masculinity' (Throsby and Gill 2004:160). Many patients are only able to undergo the treatment process by concealing that they can't cope and not acknowledging that it has an impact on their close relationships and other aspects of their lives. They wish to conceal this inability to cope both from themselves and from others and being seen to come to a counsellor is exposing this.

#### 7.4.4 Barriers Coming Down: Wider Society's Perception of Counselling

Counsellors who have been working in the fertility field for over 10 years commented that their perception is that slowly there is an increasing societal

acceptance of counselling. Many acknowledged the fact, that counselling as a service has become more prolific generally in health and social service settings in the UK. It was mentioned by one counsellor that the media gives far more positive recognition and reference to counselling than it did just a few years ago. Most counsellors felt that their service in general was getting "more and more used". They told me that modern day living appeared to be increasingly stressful and adding the stress of fertility treatment can become an "explosive process". They identified a tiny minority of patients who felt that the service provided at the clinic provided them with an exciting first opportunity in their lives to have free counselling. Counselling is an expensive commodity (even charitable based organisations such as Relate in the UK charge fee starting at £44 hourly for marriage counselling in 2011). Such clients were described as "lovely people to work with because they were really into it". Many counsellors commented that they felt that the aversion to counselling for many was cultural and unique to the United Kingdom. People were of the opinion that there was something seriously wrong with them if they have to see a counsellor. These findings again reflect Throsby and Gill's findings, when fear and secrecy was shown to surround patient support networks and mechanisms (Throsby and Gill 2004). This is because the decision to undergo counselling or other therapies risks signalling to people in their lives the sensitivity of their situation. There may also even be a perceived risk of social exclusion and chance of becoming objects of pity. This attitude is not thought to prevail in other countries, particularly not in North America.

#### 7.4.5 Patients' Need to Focus on Medical Issues

Counsellors felt that the sessions they offered were low down on the list of patients' priority in terms of time and need. Patients undergoing fertility treatment 'need' blood tests, hormone injections, ultrasound and so on. One counsellor felt focusing on the physical aspects of the fertility treatment and sinking into a "clinical mode" is a patient's "psychological mechanism of dealing with stress". Procedures in the clinic could be orderly, managed and to a certain extent controlled in a way that discussion in a counselling room could not. By conforming to and immersing themselves in the clinical procedure the IVF patients endorse what Cussins



describes as the 'routinisation' of clinic life (Cussins 1996). The patients help to naturalise the technology. Patients enrolled upon a programme of infertility treatment clearly have a lot going on both physically and mentally. One counsellor was of the opinion that few patients "have the peace of mind to sit with a counsellor and reflect" upon the treatment. The patient is wholly focused upon the single goal of having a baby and they "want it yesterday". Patients are reluctant to think or talk about anything else. This can impede implications counselling greatly because many patients will find it difficult to perceive or accept that there would be any problem with any kind of pregnancy. Furthermore, patients undergoing such fertility treatment may have difficulty thinking beyond or perceiving outside of the immediate future.

#### 7.4.6 Patients' Loss of a Sense of Control

Another finding in my interviews, which confirms the sociological notion of order and control, was also discussed in Cussins' research of US clinics (1996; 1998). Order and control can be concepts that fertility patients internalise to help organise and justify the use of a highly invasive, stressful and largely unsuccessful medical solution to their infertility. IVF still has a less than 50% chance of success per cycle. Added to this many couples have been attempting to get pregnant for a long time before treatment and therefore are already feeling a lack of control over their bodies. My interviews indicated a confirmation by several counsellors that they felt that during the IVF procedure the option of whether or not to undertake counselling is the only process that the patient has any choice over. Here a patient has an opportunity to assert autonomy over the fertility treatment where they are under complete instruction and care of the clinicians and clinic procedures. Only here, throughout the option of counselling are they able to say "No". One counsellor suggests that an 'open- door' policy where patients can come back whenever they wish to puts a patient back in control of whether or not they wish to see the counsellor again. The fertility clinic provides that patient with an institutionalised programme of treatment. This very often means that patients are required to

delegate control over fundamental bodily functions. Control, therefore is a very big issue for patients because it has essentially been taken away from them in a broad variety of ways. Offering the patient control over the support offered through counselling is a way to promote patient autonomy.

#### 7.4.7 Costs: Money, Time and Convenience

Other barriers may be money, although many clinics offer unlimited sessions. Clinics offering unlimited free sessions find they have more patient DNAs (do not arrive) than those where patients are required to pay per session. When people pay, the session becomes more valuable. Time is another barrier as clinics cater to a large geographical area, to come a long way especially for a counselling session is hard. Many patients will make a day trip for their infertility treatment appointment. These appointments may be scheduled hastily depending upon where a woman is in her cycle. Patients will want to combine their clinic appointments with counselling appointments and the counsellor may not always be readily available when they need them. However, many clinics offer telephone counselling to endeavour to overcome this barrier.

#### 7.4.8 Differences in Clinics' Policies and Funding of Counselling

The further major barrier for patients accessing counselling as perceived by counsellors was described as the 'culture' of the unit. This is whether or not an individual clinic promotes and encourages counselling. In general, it seemed that counselling was more promoted and encouraged in clinics that had a majority of NHS patients. These clinics were described by the counsellors as "NHS clinics". In these clinics counselling was accessible offering an 'open-door' policy (patients may make an appointment/walk-in whenever they wish to), open-ended (not contracted for a series of sessions) and available free before, during and after fertility treatment. Another observation was that larger clinics offered better counselling services than smaller clinics regardless of their patient population. Small clinics and some larger clinics with a sole private patient base were described as not incorporating counselling into the culture of the clinic. Private

clinics appear to operate on a different business model and more pressure is exerted upon staff by hospital management to bring in business. In these types of clinics patients are mostly referred, as opposed to self-referred, and more often only see a counsellor to discuss the implications of complex treatments. Such sessions are described to be largely information giving. This satisfies the HFEA's formal policy with regard to counselling and grants the clinic its licence. If a patient came to a counsellor at other times it was likely to be because clinicians or other staff perceived them to be 'not coping'. These clinics were not promoting visits to counsellors simply because it is helpful for anybody in a stressful situation to talk and get support.

#### 7.4.9 Attitudes of the Clinical Team

Within any individual clinic some clinicians and other health professional were deemed to promote counselling more than others. It may be a simple issue of personality. Some people are more open and positive about the concept of psychological support than others. They are simply more interested in people's psychological health than others. It was observed that there was a gender divide: more patients were referred to counsellors through female clinicians.

“We've got both male and female doctors and predominately more patients come through the female clinicians than the men”

(UK infertility counsellor)

There was also a clear commentary about a cultural divide. A clinician or health professional's cultural perspective will influence whether or not they recommend counselling. Some cultures will foster secrecy within the issue of infertility. The subject is private and talking about it is not considered acceptable. Other clinicians may themselves feel threatened professionally by the counselling service. They may be under pressure from hospital managers to see as many patients as possible. The counselling service may interfere with their work and question their

professional capability. The general awareness and promotion of counselling through all levels of staff has an impact upon the patient's perception of the service. It was felt that if nurses, administration staff and others actively encouraged patients to go to visit the counsellor then they would. The culture of the clinic as a unit in its entirety reflects on each patient as an individual. Most counsellors told me that patients frequently comment that counselling wasn't offered to them in the right way. Staff at the clinic did not explain what exactly the service was and how and why it could benefit them. This was reflected in commentary in the House of Commons Select Committee Report 2004. The report gave a discussion of how generally counselling was not respected by other members of the fertility team: 'It has been apparent during this inquiry that the value of counselling is not fully appreciated by clinicians, and indeed some seem to regard it with thinly disguised contempt' (House of Commons 2004). Contempt is a strong description of clinical conduct, however, the report recommended this be resolved by professional and managerial clinical practice rather than legislative means.

## **7.5 Findings: Counsellor Centred Issues**

### **Implications, Support and Therapeutic Counselling**

**Counsellors told me that their service was categorised according to the needs of patients. Patient needs are however ultimately dictated by the individual IVF clinic and its policy pertaining to counselling and the level of provision it deems relevant to its daily functioning. The type and frequency of counselling offered at any one clinic will reflect this. The three clearly defined categories of Implications, Support and Therapeutic counselling, came about when developing legislation governing reproductive technology. THE HFE Act 1990 requires the offer of counselling to be made to all prospective recipients of treatments services and well as to donors and those seeking information from the HFEA concerning their origins. As part**

**of its responsibilities under the Act, the HFEA is required to produce a code of practice and consider the quality of counselling facilities to ensure licensing conditions are met. To facilitate this the Department of Health requested the assistance of the King's Fund Centre in 1991, which established a 10 member interdisciplinary committee of specialists. This committee identified 3 categories of counselling. They felt that any clinic could offer information counselling (a combination of information, advice and discussion), in addition to the 3 other forms of counselling without formal counselling training (Blyth, Hunt 1994). The 3 counselling categories are apparent in the HFEA guidance. Categories can be useful in explaining the function of the service to prospective patients. All except one of the counsellors were of the opinion that these categories give patients who don't know anything about counselling definitions, explanations and options. Counselling has been broken down into these three categories in all HFEA codes of practice except the current 8th code of practice (current for this year, 2012).**

“there wouldn't be anybody in any of the clinics who wouldn't have heard of these categories”

(UK infertility counsellor)

“now that these three categories have been taken out we realise how useful they were”

(UK infertility counsellor/clinic director)

### 7.5.1 Implications Counselling

All counsellors told me that implications counselling was the type of service they gave most frequently. Implications counselling occurs at the start of the treatment. All the interviewees told me that the offer of this type of counselling was mandatory

for certain treatments in accordance with HFEA and clinic policy and very often only one free session is offered or accepted. This results in a great challenge for any counsellor as in addition to developing a relationship with the client(s) and building trust many complex issues need to be discussed in a time frame of somewhere about 50 minutes. Implications counselling involves a very focused conversation involving the discussion of issues surrounding the welfare of the child who is conceived as the result of donor material. The complexities of new family relationships and the context into which they may bring a prospective child have the opportunity to be skilfully discussed and analysed. In a session the counsellor will attempt to help patients see their possible future child's perspective.

Many counsellors told me that it is very hard for a patient to visualise any event past the immediate goal of getting pregnant. For any patient the idea that they may be going to have a child is so wonderful and exciting that to be asked about how they are going to feel in 18 years, when the child wants to trace their genetic parent often seems totally irrelevant. Most couples are totally absorbed with the goal of having a baby. One counsellor quoted a prospective parent as saying "I just want a baby, we will do anything you say". Patients are very often thinking about their own needs and not the future of any hoped for child. All counsellors thought that the distinction between implications counselling and support counselling may get blurred because many clients can be seen to get quite a lot of support from the sessions.

#### 7.5.2 Support Counselling

Support counselling refers to discussion that will support the patient during the treatment process. Any difficulties arising as a direct result of the fertility treatment will be discussed. Patients may fear needles or have high anxiety around particular medical procedures. One counsellor told me that if a patient has a tendency towards anxiety, a counsellor might analyse how they have coped in past situations and look at what has worked and not worked. This may help them to understand better how their psyche works and support themselves and make use of the support systems available to them. Some patients may need to lose weight

in order to improve their chances of conception. Patients may express feelings of isolation or loneliness whilst undergoing the treatment. Other patients may come to counselling terrified, upset or have had treatment failure. Many seek stress management to cope with the demands of the treatment itself. This occurs particularly in relation to a patient's work and work related stress. The counsellors that I interviewed were of the opinion that the majority of patients don't get support from their work-place to go to appointments. They told me that many patients find it helpful to come and discuss this subject with a counsellor as it has implications for them moving forward with treatment.

All counsellors told me that very few patients would deal with anxiety before they have had treatment. I was told that the majority of clients come for counselling when they have not been successful, either after a first treatment or after suffering cumulative loss from multiple disappointments. Patients will discuss the past treatment(s) and clarify issues of blame "was it their fault that it didn't work". Strategies and tactics that may help them to help themselves, as they move forward onto a subsequent course of treatment, can then be discussed. Many patients come for support counselling when they are not sure how to proceed or have made the decision to end treatment. Topics discussed will include treatment options with donor material, surrogacy, adoption or moving on without a family.

### 7.5.3 Therapeutic Counselling

The counsellors explained to me that therapeutic counselling may get blurred with support counselling because all counselling is considered to be both therapeutic and supportive.

"All counselling has a therapeutic element"

(UK infertility clinic counsellor)

Support is never "divorced" from any type of counselling. This means that the HFEA categories are often "fudged". All counsellors told me that the three

categories were integrated. However, implications' counselling often slightly differs from support and therapeutic counselling because a counsellor will bring prescribed topics into the room to be raised with patients. With the other categories of counselling the counsellor takes what a patient wants to bring into the room. The counsellor's descriptions of therapeutic counselling included "walking alongside an individual or couple to let them express their pain and sorrow" and "allowing them to perhaps come to terms with the fact that they won't have children". One interviewee simply described sessions as an "opportunity to be listened to and heard".

Therapeutic counselling may occur with support counselling. Also, in clinics where patients are able to access unlimited counselling before, during and after treatment, support counselling may turn into therapeutic counselling after treatment has ceased and many clients will continue counselling for some years both after successful and unsuccessful treatment. Subjects covered very often refer to substantial problems and may include an in-depth bereavement experience associated with treatment such as miscarriage, early death or genetic abnormality. In addition to this it was mentioned to me that general bereavement issues frequently arise in counselling sessions such as the recent loss of a parent. I was told that this is because the fertility treatment itself touches on the fundamental issue of new life, which often raises fundamental issues of death. Existing relationship or sexual problems may also arise during the course of treatment. I was told that very often a male partner would not discuss the treatment or his feelings surrounding it because he feels it is up to him to look after a 'non-coping' partner and often a counsellor can identify this and allow that party permission to talk. This gender division in emotional adjustment to treatment supports Throsby's findings (2004). Another counsellor suggested to me that very often the parties within a couple have two very different agendas and are often not listening to each other in circumstances that are both difficult and stressful. Coming to counselling offers the opportunity to explore their thoughts and feelings about the fertility treatment and the overall situation that they are in. This allows them to function during the treatment more as a team offering mutual support to one another. Alcohol or addiction to other substances was an often referred to topic.



Counsellors often mentioned therapy, which discusses the emotion envy. It is a strong emotion and many infertile people find themselves for the first time ever envying people in their lives that they very much love. They view everyone else they know as able to be/is pregnant or having children. This envy has an impact on the relationship of the infertile couple and all other relationships surrounding them. Another frequently discussed emotion is that of loss. There is a loss occurred due to not being able to conceive naturally and a loss of time, hope, choice and control. This loss results in grief, resentment and anger. Counsellors will discuss how such loss is making the patient feel and offer techniques to lift their mood. Sometimes sessions simply involve a patient being listened to and heard. In larger clinics where more than one counsellor is available, the skills of any counsellor will be matched with the needs of the patient.

One counsellor told me "People are not just infertile, they are human beings and have a history". Therapeutic counselling can become a conversation about themselves, as such, and in many ways therapeutic counselling was described to me as being less specific, looking more generally at how infertility impacts their lives. The requirement for this type of counselling is dependent upon the background of each client. Life experiences may make infertility particularly difficult to deal with and influence their personal resources. I was told that when individuals are under pressure early life issues could re-emerge. A patient can go into despair or clinical depression because their own resources are much reduced because of these early life issues. In such instances it may be necessary to ask a client's consent to write to another agency e.g. their G.P. and get additional help with medication before continuing counselling. The extent of external support from family and friends may also influence individuals counselling needs.

Counsellors told me that during any session they would attempt to encourage clients to bring things to the surface and "name what they see". They consider it their job to gauge the situation and try to help the patient talk things through in order to gain a more "balanced" view of the situation they are in. One counsellor stated that "we are not the experts in people's lives, people are the experts in their own lives". She described her primary work as trying to help patients express what

it means to them to go through the process of fertility treatment and acknowledge the enormity of its impact. However, when couples display severe problems that are not associated with the infertility treatment and such problems could benefit from regular therapy counsellors will refer "them out" to other services in another therapeutic setting. Before doing this, counsellors will talk to patients about what ongoing therapy might be like somewhere else. Even counsellors working at clinics that offer unlimited sessions before, during and after treatment acknowledge that they are working within constraints. They may see a patient for years, over concerns associated with fertility treatment or for an intense and concentrated period when there is a crisis. However, counsellors are not available for regular therapy sessions for long- standing problems unassociated with the fertility treatment proper.

There can be a demand for counselling at any stage of the IVF treatment. Counsellors will see patients for what they categorised as 'crisis' sessions, when a patient is in a time of deep need throughout the IVF cycle. Topics discussed in such sessions will be depression and anxiety as a result of the treatment, relationship strain because of treatment and issues regarding work, other family members and partners that arise because of the strain of treatment.

However, I was repeatedly told that most patients come to counselling after IVF failures. Aside from those patients taking implications counselling, it is rare to see a patient for the first time before treatment, as currently a very small percentage of patients will see a counsellor to address anxiety issues at this time. It is rare to see patients at all during their first IVF cycle. Counsellors told me that patients might come after their first failed cycle. I was told that "It is often not until patients have had their first experience of IVF that they know how hard it is". Patients most often visit the counselling service for the first time after a third or fourth cycle. At this point they have suffered cumulative loss.

Another time of very high anxiety was repeatedly identified in the days after implantation and prior to the pregnancy test. This was described as a 'terrible limbo period" and is an obvious time of elevated anxiety. However, I was told that

only those patients with an established and ongoing relationship with a counsellor or the counselling service would seek professional support at this time. Other patients are likely to ring the counselling support line or use on-line web forums for support. Many patients will rely on the support of the doctors and nurses in the clinic who they know well by this stage.

As mentioned above, a very difficult time for patients is when they must make the decision to end treatment and no longer engage in the IVF process.

“The most difficult time for patients is making the decision whether to end treatment and not do anymore”

(UK infertility counsellor)

Many clinics have developed specific literature for patients to read at this time. Titles include "Following Unsuccessful Treatment". Such leaflets attempt to recognise the feeling patients are likely to have following a failed IVF cycle and outline how the clinic approaches such a failure and what the patient's next course of action can be. Details of counselling available at the clinic will be given plus contact information for other agencies such as adoption advice. This is a time when patients are most likely to ring the counselling service. At this time several sessions of counselling are commonly taken. Topics discussed may include adoption, egg donor programmes, surrogacy and moving on without a family. Often a patient will be seeking emotional support or stress management guidance in order to cope with the pain, stress and loss involved with the failure of the treatment itself.

## **7.6 Multiple Births**

**I discovered from my interviews with counsellors that their current involvement with promoting SET at a clinic level was currently absolutely minimal and that any information regarding SET was usually outlined in leaflets and sometimes elaborated upon by medics depending upon how**

**strong the clinics promotion of SET procedure is.**

#### 7.6.1 Clinician and Counsellor Involvement

The clinicians most often raise the issue of multiple births as part of the information giving process in the initial consultation with any patient. The clinic's policy with regard to SET is often clearly outlined in patient information material. The issue may then be raised later with the embryologist and if the clinic has a strong SET policy and the patient is a suitable candidate then one good embryo will be replaced. Counsellors all said they were given clinic policy on multiples birth policy. However, at the time of interview I was told that if there was any detailed discussion with a patient then it most often took place between the medics and patients.

Counsellors are also usually involved in further clarification about the implications of multiple pregnancy when they are seeing a surrogate for implications counselling. Discussion with the surrogate will cover medical implications of a multiple pregnancy and testing and reduction of multiple pregnancy. Such counselling is most often a mandatory stipulation by the clinic and exists to give full information about the procedure to the surrogate before she consents to it.

I was told repeatedly that counselling should not be directive in any situation. Counsellors try very hard not to be directive and always encourage open discussion in any session. With regard to multiple births a counsellor must recognise the reasons why a patient is speaking so positively about the idea and then raise some issues where difficulties might arise with regard to a multiple pregnancy. From here they would direct a patient to look at more information so that they could learn something more about multiple births. One counsellor told me that being "directive in counselling is a contradiction in terms, raising awareness is as much as I would expect to do".

When I asked the counsellors question number 8: "How would you best describe the majority of patients' attitudes and feelings about the likelihood of a treatment

resulting in a multiple birth?" The response of many of the counsellors was that this prospect was getting less frequent because of the HFEA mandate to reduce multiple births. However it was reported to me that most patients felt (before SET or not undergoing SET) that if it was among the risks associated with treatment that they could cope with twins. I was told that a large percentage of patients thought it was "lovely to get all their children in one go". I was told that patients were very often unable to imagine the implications of what twins may be like. They say they would be relieved "not to have to go through this again". It is very hard to appreciate what the additional pressure on time and other resources would be like for themselves, their relationships and their health. When clients are "desperate" to have one baby, it is very difficult to conceptualise babies as being problems. One counsellor told me that for many patients "two babies can be seen as such a wonderful, wonderful possibility compared to none". Also, as I mentioned earlier, being unable to conceptualise twins may be connected to difficulties in projecting past the immediate goal of achieving pregnancy, making it difficult to project future possibilities. Counsellors told me that they rarely came across patients who did not want to carry more than one child although lots were worried about carrying more than two.

"Of the counselling clients I see, (I can't speak for the clinic clients as a whole) most of them think they could cope with twins. They think that they could cope with two but people are very worried about having three"

(UK infertility counsellor/clinic director)

In addition to physical risks, their worries about coping with more than one baby were described to me as both emotionally and financially coping: two babies can place extra strain on emotional capacity due to the extra responsibility of daily care and the extra expenses that go with this care. I was told that patients after finishing treatment mostly donate or do not ever use their embryos, as the majority don't want more than two babies.

“One client had identical twins from a single-embryo transfer and didn’t think they could cope financially or emotionally, but they did. However they are now absolutely clear that this is the end of their family”

(UK infertility counsellor)

Two counsellors told me that running a regular ‘Reproductive Ethics’ meeting had become a useful part of clinical practice at their workplace. They thought that this can give the opportunity for the team to meet and discuss ethical issues surrounding treatment and act as a forum for the counsellor to voice concerns and issues that may be raised in sessions. I was informed that on occasion, issues surrounding multiple gestation had been raised at these meetings and discussed at a team level.

#### 7.6.2 Single Embryo Transfer Policy

Many counsellors told me that their clinics were part of an informal regional SET policy. One such agreement has been in place for at least a year in across the West Midlands and one of the counsellors reported that it had contributed to a significant decrease in the rate of multiple pregnancies at her clinic. The NHS is also supporting SET, in some areas PCTs won't allow any more than one embryo to be replaced in any woman under 35 years old as a condition of funding.

Single embryo transfer has not produced the desired result of a multiple birth rate substantially below 20%. Due to time lapses for data collection and recording, not all the data from recent cycles are available. According to many counsellors their clinics are not worrying as they mostly are feeling that this is one of the HFEA objectives that they have met. They told me that the multiple birth directive has implications for the advice clinicians and nurses give but currently, not so much for counsellors. Medical staff now do a lot of 'counselling' around SET and multiple births in the initial consultation with any patient.

SET has decreased the likelihood of twins and this is coupled by an increased awareness by the public of the complications associated with a multiple pregnancy

and birth. I was told that just a few years ago counsellors were working far more frequently with patients who were pregnant with or had given birth to multiples and the issues arising from such situations.

Although counsellors were able to give me only an impressionistic view, it appears that not all clinics routinely subscribed to SET. I was told by a counsellor at a small private clinic that SET was "only occasionally" used and counsellors at other clinics told me that the number of embryos replaced in any patient was a clinical and laboratory decision. This means that at that clinic each individual treatment is based on the likelihood of success. The embryologist indicates the quality of the embryos and grades them according to their chance of success and the clinician looks at the chance of success of the women they are working with. One counsellor at another small private clinic told me that if a patient is wholly responsible for the cost of treatment and insists on two embryos being replaced then the clinic will honour these wishes providing that full disclosure of all the medical implications regarding a multiple pregnancy have been given and that the advantages of SET have been stated.

After a discussion of my interviews was published (Journal of fertility Counselling, Spring 2011), I was invited to give a talk about my research at the Southern Regional Fertility Counsellor's forum. I gave this talk in Bristol on October 2nd 2011. It was insightful for me to be able to discuss my research with counsellors in person and talk about the topics my research raised with them and how these issues influenced the counsellors in their practice on a day to day basis.

In summary, evidence from the counsellors that I spoke with indicates that the adoption of promoting elective single embryo transfer within any clinic in the UK is not uniform. From my interviews it appears that this multiple birth reduction policy is less of a priority in private sector clinics. It is also not usual for patients to approach the counselling service until they have experienced IVF failure. This also makes it less likely that the counsellor will have the opportunity to discuss SET and multiple births. Such discussions need to take place before treatment begins.

## CHAPTER EIGHT

### FINDINGS: PATIENT OPINION ON UK INTERNET SUPPORT SITES

The next part of my investigation, as detailed in this chapter, is an analysis of online communities that exist to support patients who are going through the IVF process. Going on-line eliminated the need for a formal interview process. As a researcher, I observed opinions online in a systematic fashion.

As subjects of the IVF clinical process I considered patient opinions and reflections to be important when considering public policy concerning their healthcare options. The sites that I visited provided IVF patients with a collective focus and a collective way of working on issues that were fundamentally different and very personal to them. My aim was to ascertain what patients' opinions were with regard to the possibility of having a multiple pregnancy/birth and their views on single embryo transfer. This discussion aims to provide support for my hypothesis that increasing support and discussion forums in the IVF clinic, particularly in the form of increased counselling can help to promote single embryo transfer.

#### 8.1 Analysis of Fertility Support Sites not attached to clinics

The first chatsite that I analysed was 'Fertility Friends', this appeared to be the largest chatsite and most respected by the clinics I approached. I joined the site as a member and was asked to give my reasons for joining. Any application had to fill in an explanation for joining and this was mandatory before consideration of the application could begin. It was here that I disclosed my status as a researcher and declared the University that I was attached to. The administrative team of the site vetted my application before I was given permission to join. I used a fabricated name for the site and any respondents that I cite for the purpose of this investigation remain anonymous. I am interested for the purpose of gaining patient perspectives for my thesis to glean opinions about multiple births and single embryo transfer. Within this site, I was able to conduct a search under these two topics and patient opinion has been observed from 2004 until January 2012.



Patients reporting to the site were all aware that having a multiple pregnancy was a higher risk pregnancy. Health risks are implicated to both the mother and to the babies that they are carrying. Multiple gestations seem to be highlighted as a major risk to the majority of patients reporting to the site and risks were mostly explained at the patient's first appointment with the clinic. However, statistics giving the patient's chances of a multiple birth were highly variable across patients and across clinics and a clinic's policy to reduce multiple birth rates was also reported to be variable.

One of the first documentations of an individual's encounter with a multiple gestation on this particular site was very poignant and sad to read. The patient described herself to be "over the moon" at the news that she was to be having twins. However they were born and died prematurely at 23 weeks as a result of complications involving the nature of the pregnancy. This patient posted that "words cannot express how I feel to have been pregnant for 6 months and to have it all snatched from me. I would chop my arms and legs off if I could still be pregnant. Life is so cruel". Another respondent documented her twins being born at 23 weeks, as her uterus couldn't support the pregnancy. She says that: "I nearly died along with my children. I really think that everyone should all seriously think about multiple births more. It's the highest risk group for losing babies in the second and even third trimester and I would not wish what myself and my husband have been though on anybody, its truly horrific."

The Human Fertilisation & Embryology Act requires that clinics consider the welfare of the child born from any procedure (Human Fertilisation and Embryology Act 2008). Correctly considering this point of law means that each clinic needs to address the health issues that arise to the child from the environment offered by a multiple gestation. This factor is a key stimulus for the HFEA's multiple birth reduction policy. Patient opinion on this site however, did not voice universal support for the 'welfare principle'. For many patients, finances were a major concern and they felt if they were paying for treatment, the number of embryos that were transferred (either one or two) should be their own choice "especially if we

are paying as not all multiple births end in disaster”.

IVF can have an enormous impact on the economic structure of the family unit. As one patient put it: “to tell us when we are paying over £5000 per go that we can’t have 2 embryo’s transferred for risk of having twins is totally unreasonable as far as we are concerned”. However, the family unit has not got to bear the cost of hospitalisation and treatment for the improvisation to health to the babies and mother’s who receive two embryos. Patient responses were extremely focused upon the IVF treatment and not upon the long-term sequence of events resulting in the treatment. A summary of a typical response to the proposal of elective SET was “I believe it is our choice as private patients who pay for this treatment to have the right to choose if we want one or two embryos. I personally would love twins so putting two back was very important to me and my partner”. Patients were more vociferous about not accepting elective SET when paying for treatment.

However many NHS funded patients thought that instead of a clinic being wholly committed to SET, that clinics should conduct detailed individual assessments. They wanted more carefully considered treatment plans at the outset of treatment, specifically addressing the individual’s history and implantation issues concerning their embryos. Patients said that they were generally more comfortable trying SET if their embryos had reached blastocyst stage.

One IVF patient objected to SET because she felt that it might mean a woman would need to go through more IVF cycles to get pregnant than with a double embryo transfer. Her concern was that the long-term effects of high dose hormones used in the IVF cycle have not been documented, for example, the risk of ovarian cancer 25 years after treatment. I felt that this patient overlooked the fact that elective SET required surplus embryos to be frozen and used in further cycles. These further cycles mostly do not involve hormone treatment. So any patient using SET should not be subjected to any more hormones than a patient who implanted all the embryos when they were created. The patient went on to discuss the high emotional cost involved in participating in the IVF treatment cycle both on the patient and her loved ones. Each IVF cycle, in her opinion, undermined both the emotional and economic stability of the family. In my opinion, this point

was very valid. Many commentators talked of the stress involved in the treatment and used the site for support. One user described this “website as a godsend”. She said that “I hate life for making us go through this torture and you only realise how inhumane and mechanical it makes you feel once it is over”. There is a cost and a stress factor involved in the procedure to replace the frozen embryos. The cost is significantly reduced compared to a full cycle of IVF but the tense two week wait after embryo(s) are replaced and before the pregnancy test is the same. In addition there has been very little research into the short or long-term effects of freezing on the embryo in terms of any long-term health consequences for the child born later. Another site user explained that she had had to use medication for her frozen cycle in a similar fashion as she did with her fresh cycle, as her natural hormone levels were low. These drugs had common negative effects upon her health. She then went on to discover after taking the drugs to prepare her for the transfer that none of the healthy blastocysts that were frozen survived the defrosting process. She told the site that “to describe our heartache and disappointment is too much”. For some patients there may be a risk that the freezing process could negatively impact the structure of both embryos and blastocysts.

There was some discussion about the use of fetal reduction as an alternative to SET. All posts in response to this discussion were not in favour of widespread use of the technique except in cases where the health of the babies or the parent was seriously compromised by the multiple gestation. One comment that summarised the rest of the responses was that “if it is true that 50% of IVF twin pregnancies go without a hitch, then removing a twin with no other issue that to keep the number of twins down is barbaric”.

One page was dedicated to patients’ choice about the number of embryos to transfer. All the patients who conversed on this page felt that the decision should be based upon the quality of their embryos coupled with whether or not these embryos were cultured to blastocysts. However from reading the posts I felt that patients were very much more inclined NOT to opt for eSET. Posts came predominantly from women who had chosen to transfer two embryos. Those who

had chosen to transfer two and had conceived twins were glad. One patient who suffered severe complications and hospitalisation during her twin pregnancy said that “I would not change my decision even with the benefit of hindsight”. Another mother wrote that she had lost “both our boys at 23 weeks and 5 days, this was heartbreaking and still is”. However she went on to say that “even though we lost our twins it will not put me off having two embryos transferred again”. With reference to a proposed future IVF treatment she said that she would be “hoping and praying that we get twins again”. Those patients that had opted to transfer two embryos that had resulted in a singleton pregnancy wondered that “If they had chosen one embryo to have transferred, would they still be childless?” As one parent put it “It concerns me that had I had 1 embryo transferred, it might have been the 'wrong' embryo”. On this site there was no grand support or praise for SET on behalf of the patients. However twin tragedies were recorded and lots of accounts of extended hospitalisation the cost of which in the UK is borne by the state. Cost to the health care system was acknowledged by site users but not necessarily seen as an equitable motivation to enforce policy. Many site users were of the opinion that the policy was being pressed purely for “financial reasons”. They did not like the fact that consultants discussed statistics and explained the HFEA mandate to reduce multiple rates. As one patient put it “I personally don't care about their figures”.

One parent of twins offered some insight into the psychosocial impact of twins on the family unit. The time taken to feed and change two babies is tremendous and places a strain on the family especially when there are other siblings. This parent says that “I can only describe the first year as absolute hell! I know that when you are desperate to have a baby that a twin pregnancy seems to be a double blessing but the reality can be different. Easy for me to say, I know I have children already, but it really is so difficult and a completely different pregnancy from a singleton birth”. Another twin parent commented that “twins are hard work. If they're both crying at the same time you want to cuddle them both but when you're alone it's not always possible to give them individual attention and they are often both placed in their bouncy chairs and rocked instead. I suffer a lot of guilt because of this. Not to mention the heartache suffered when for the first two weeks of their life I couldn't

be Mummy to them properly. I understand the desire to be able have two children from one IVF cycle, believe me I've been there, but it isn't just about creating an "instant family". It's far more complicated than that". These perspectives were valuable as they reflected the views of respondents with multiple children and healthy ones at that. Other respondents were basing their views and opinions on the idea or fantasy of having twins at home.

I searched within the site for respondents' opinions at the time that the consultation process was in place for the development of public policy by the HFEA to implement and promote SET. This was in the first part of 2007. My interpretation of the figures supplied by the HFEA at that time was that in the UK, one in four IVF pregnancies resulted in a multiple birth. Therefore, 25% of IVF pregnancies were multiple with the maximum recommended embryos for transfer being two, three in exceptional circumstances. Half of IVF multiple babies, or 12.5% of all IVF births were in need of neo-natal care and many of these went on to suffer long-term health problems. The other half suffered low birth weight but went on to have a good quality of life much like any other singleton. In 2007, the HFEA's recommendation and subsequent implementation of policy proposed a reduction of multiple births to 10% of all IVF pregnancies, staged in over a number of years (HFEA 2007). This means that one in ten IVF pregnancies would be multiple which is still ten times the natural multiple birth rate of one in one hundred. However there is a reduction in neonatal care from 12.5% (when the multiple IVF rate is 25%) of these twins to 5% (if the multiple IVF rate reaches its goal of 10%).

Several patients had attended HFEA consultation meetings. In total 3 were held for IVF patients across the UK and participants were offered £70 to cover their expenses for that day. Alternatively IVF patients could voice their opinion by responding to an HFEA online or in the mail questionnaire. One IVF patient who attended a consultation meeting was extremely pro SET. She said that she had gained extreme comfort from using the 'Fertility Friends' website and that it was a "supportive place to discuss fragile issues". Her infertility journey had involved giving births to twins who "lived for some hours and in the end we had to turn the life support machine off for both of them as they were too young and ill...personally

I would never ever risk having two embryos put back and risk my life, I could have died from the infection that got into my womb, or the life of the child. We all feel differently and have different circumstances but I feel really strongly about SET. There are too many babies dying as a result of multiple pregnancies”.

Some parents openly admitted that they could only support SET in light of what they had experienced. One lady reported her heartache of conceiving quadruplets after travelling to India for treatment to save cost. All babies died halfway throughout the pregnancy. Another parent described a postpartum haemorrhage (PPT), which is five times more common with multiple births due to the amount of overextension in the womb making it slower to contract (Senat 1998). This dangerously incapacitated her after labour for many days causing extreme emotional stress, as she was unable to bond or breastfeed her babies. Another parent lost one of her twins. The twin who lived “spent 15 weeks in hospital and is scarred for life from all the endless needle pricks for blood gases. I would NEVER knowing what I know now risk a twin pregnancy again. I was warned that if I had a two embryo transfer that I may conceive twins but I was never fully made aware of the risks of a twin pregnancy. I can’t say that had I been that I would have chosen a SET - of course I wouldn’t - I was desperate for a baby - and would have taken my chances.” A couple of site users reported that their single embryo transfer had resulted in twins as a result of the embryo splitting. One of these mothers said that her clinic only offered the choice of SET given her age and the quality of her embryos. However, “I’m so glad that I didn’t have two embryos put back, because I could have ended up with triplets/quads”.

These respondents were in the minority. Most site users at the time of the consultation were not in support of SET despite attending the HFEA meetings and hearing what the specialists at the meetings had to say. The majority of IVF patients wanted to choose the number of embryos they transferred especially when paying for treatment. One IVF patient felt that “It’s absolutely criminal that people with no understanding whatsoever of our grief can be allowed to even discuss contemplating our freedom of choice”. They felt the HFEA proposals were about saving money for the NHS and felt those who were overweight, drug or alcohol

users or suffering various other socio-economic problems, just as frequently utilised that intensive care. Only IVF patients were “discriminated against”. It was furthermore discussed that the HFEA and clinics would actually ‘make money’ through more patients having to have more cycles. Financial concerns feature as a dominant topic in discussion and debate surrounding decisions pertaining to numbers of embryos to transfer. One IVF patient suggested that an alternative public health policy to address multiple births would be to allow longer maternity leave for women carrying more than one child. Many experts recommend rest from five months in the pregnancy to accommodate the extra stress on the body resulting from more than one baby. This rest could prevent the risk of premature birth and contribute to easing pressure on neo-natal units. She pointed out that “anyone giving birth to two babies separately would be allowed eighteen months paid maternity leave”. Several other patients reported that they felt that NHS clinics were far more concerned about multiple births than private clinics. One site user started a poll on 26<sup>th</sup> July 2009. There were 127 responses to this poll. Her question was “If you had free choice, would you elect for one or two embryos for transfer”. From the responses it was calculated that 14.3% of respondents chose one embryo and 85.7% chose two. Reading postings in the last year (2010-2011) I have noticed a slight increase of support for SET. After searching for postings about SET it was apparent that the more recent posts reflected an increase in optimism and positive comments about the procedure than those posting prior to 2010. Those who are faced with the prospect of having to have SET, as their clinic will often insist if they are under 35 with good quality embryos are often seeking support and encouragement from others who have been successful with SET. These success stories and support posts are very recently increasing in number.

The support forum offered by ‘Fertility Friends’ was organised by topic so that those suffering from fertility issues could read and write to others in similar circumstances to themselves. Topics included religious issues, clinic or regional issues, treatment cycle stage related issues and specific infertility problems such as male factor infertility or single or lesbian women using a donor. Many single and lesbian women reported that they felt very isolated within the support mechanisms their clinic offered. They felt such services catered to heterosexual

couples and that in turn these couples provided support to each other. One same sex couple commented on the value of the site saying that they were “overwhelmed by the amount and support and love that has been shown to us from fellow fertility friends”. Although these posts were unrelated to multiple births, they demonstrate both an openness and desire by IVF patients to use and find benefit from services (such as counselling) to free them from the isolation that may be inherent in the clinical treatment.

It was notable to me as an observer that many women across the range of categories of patient that were accommodated by this site repeatedly used strong language such as “devastated”, “gutted”, “numb” or “heart-broken” to describe the feelings they encountered during treatment cycles and their resulting disappointments. Many patients described the “struggle” of putting themselves through repeated cycles, often over ten IVF cycles. This, for me, reinforced the merits of offering counselling and other support services for all patients. When I looked specifically for patients affected by triplet outcomes, I found that most of those writing lost their triplets to a premature labour as a result of pregnancy complications. Other triplets died in utero leaving surviving siblings.

Very often the triplets were a result of transferring two embryos and one of those embryos split. There is speculation that IVF embryos have a higher tendency to do this. Payne and colleagues at the Mio Fertility Clinic used special “time-lapse” computer software to observe minute by minute what was happening to single IVF embryos as they grew in the laboratory. Two of 26 blastocysts developed obvious signs that they had the potential to be identical or monozygotic twins - two distinct inner cell masses (ICMs). The cause was changes in the laboratory, called blastocyst collapse, which the researchers believe are directly related to IVF. Payne said: “It may happen because we are keeping the embryo in culture for longer until it has reached the blastocyst stage, and the formation of two ICMs during blastocyst development may be the cause of the high twin rate after extended culture.” She went on to say that it should be possible for doctors to examine embryos before transplantation and advise patients about any potential twinning risk (Payne 2008).



Of the parents who recorded their experiences over seven years on this site only four reported that they gave birth to live triplets. All these babies spent a minimum of one month in intensive care. There were also many accounts of losses for twin mothers. Often one twin died during the pregnancy and many times labour came prematurely and both twins were lost. For parents who successfully brought their multiple babies home from the hospital, the 'Fertility Friends' forum was used as a resource for support and comfort from parents in similar circumstances. Triplet parents reported feeling "out of control" financially, emotionally and practically. Support issues post-partum were vast. They included issues such as breast-feeding and teething or just to venting of frustration. A common problem is accommodating the babies in the home. Moving when carrying multiple babies during a fragile pregnancy produces extra stress and moving with two or more infants carries different challenges. The difficulties these mothers experienced were strongly conveyed on the site and they were all in some way very isolated in their parenting. One mother said "I have never taken mine anywhere on my own" and all other triplet mothers agreed that for them this was also seldom or never. The daily logistics of managing a high order birth for a single person (of which none of the respondents were) would be amplified.

Looking at recent posts (2010 onwards), it was apparent that the HFEA policy to reduce multiple gestations was influencing practice for all clinics. Some clinics were described as making SET mandatory in women under 35, one clinic was insisting on it for women under 39. Clinics with the strongest adherence to regulation were described to be NHS run. Many women at private clinics described that they were advised to transfer one embryo but ultimately could decide between one or two. The vast majority choose two because they felt that this would maximise their chances of pregnancy. These women said that they did this with the knowledge that both themselves and their donors, husbands or partners were comfortable with this decision and its consequences. Women who had this choice at an NHS clinic often wanted to choose two because they sought twins. They stated the reason for this was that once they became pregnant once they would not be eligible for NHS funding and they wanted their baby to have a

sibling. They stated that they would never be in a position to afford IVF themselves and that was the reality of their circumstances. This outlook appears not to take into account changes in fertility clinic practice since the introduction of the latest multiple birth reduction policy (HFEA 2009). Firstly blastocysts (5-6 day embryo) are now routinely transferred to most patients. If a patient's embryos are capable of being blastocysts (and not all are) they have a higher success rate than transferring a cleavage stage (2-3 day embryo). However transferring two blastocysts has a significantly higher multiple birth rate risk than transferring two cleavage stage embryos. Clinics that are enthusiastic about subscribing to SET policy may offer frozen cycles for free, even when a patient has undergone a live birth, so affording a sibling will not always be an issue. However, not all embryos may survive the freezing process. Survival rates have significantly increased though, in recent years due to clinics using vitrification instead of cryopreservation as the latter technique has a high risk of embryos forming harmful crystals (Murakami *et al.* 2013).

The second online fertility forum that I visited was "Infertility Network UK". This site was far less frequently visited than the "Fertility Friends" site and there was much less commentary and discussion for my research with regard to Single Embryo Transfer and Multiple Births. There was one forum, which specifically discussed multiple births and SET and postings on this dated from 2008 to 2011. Participants were invited to give their opinions of SET and talk about whether or not they thought this type of treatment would be good for them if they had the option of single or double embryos transfer. An information sheet about SET was posted for those wishing to partake in the online discussion. None of the participants who responded to this post were in favour of SET. The first respondent gave two main reasons for not wanting to choose a single embryo transfer. Firstly she pointed to the great emotional and physical cost of going through repeated treatments. Single embryo transfer currently decreases the success of ones first IVF cycle by a third when compared to double embryo transfer (non-blastocyst). However, repeating cycles with frozen embryos can compensate for this. The drawback to this is that further transfers mean more IVF treatment, more time off work and more disruption to the IVF patient's body and life. This online participant posted that

“the success rates are pretty much all I care about. Maybe they shouldn't be - but to go through all of this is so difficult - you're going to do whatever you can to get the result you are so desperate for and to get your life "back-on-track". IVF treatments also come with a financial cost. Some patients are eligible for treatment and these patients may get frozen follow up treatments included in their NHS coverage. However, sometimes embryos do not respond to freezing and these require further new cycles, which may or may not be covered by the NHS depending on the patient's circumstances. Private patients will likely incur extra costs by opting for SET because they will be paying for a higher number of cycles if SET doesn't work the first time (although frozen cycles are offered at a lesser cost). The posting from the respondent described that “The funding issues and the waiting lists need to be sorted out before you will get many people signing up for SET in my opinion. The idea that some PCTs require people to have been trying for 5 years before they can get IVF is awful - and then the NHS wonders why people want to give themselves every possible chance? And why so many of us would consider twins as a perfect outcome? Hmmm!”

The second post also stated that she felt that she “was against” SET. She described how she fell pregnant with a singleton after having a double embryo transfer (DET): “ obviously one failed - and if that had been the only one we'd had then of course she wouldn't be here now”. She also said she was hospitalised for many weeks during this pregnancy as a result of complications, whilst another parent she knew of carrying twins was not hospitalised at all. The third post was partially dedicated to the difficulties and irregularities of IVF funding in the UK. This makes SET unfair and difficult to endorse nationally. Aside from funding issues the lady who wrote the response was extremely concerned with the implication for women's overall health involved in increasing the number of cycles that may be necessary after a first SET. She feels that “the stress of having a cycle shouldn't be underestimated. Personally, I would rather have DET than another cycle”. There have been no studies on the detriment to the patient's health and wellbeing for double embryo transfer over single embryo transfer. However comments such as these lend weight to increasing support mechanisms such as a counselling on a clinic level, as clinics introduce SET into their practice. Counselling can be a tool

to discuss, clarify and inform patients about SET. In addition it can be used as a tool to manage the stress that is associated with treatment. This lady finished her post by expressing: “ What I'm trying to say is that we do everything, everything, everything we can to nudge the chances up in our favour, however marginal that nudge might be and however silly or ridiculous or slender it might seem to medical professionals. So, asking us to accept a drop of a third in chances feels extraordinarily harsh.” The next post referred to funding again. This patient was keen to express that SET is a good option for using blastocyst transfer. She thought that in order to encourage SET “ the NHS should include funding of blastocyst culture (where funding is offered). We have just had our one and only funded ICSI cycle and yet still had to pay £800 for blastocyst culture” She said “ I am most certainly in favour of freezing spare embryos, as long as there are enough left to still ensure a good chance of success on a subsequent ET (taking into account that approx. 30% will not survive the freeze-thaw process)”. To enable blastocyst SET to function optimally, clinics need to offer transfer procedure 7 days a week. This needs to be coupled with the best freezing techniques. The next patient who posted had made the decision to opt for SET. This was because she had one child and wanted only two children. However she said that choosing SET was “a very emotional step to take, and a decision not made lightly”. This comment highlighted the need to consider each patient as an individual and offer opportunity to explore any emotional impact the treatment has on them. Anyone making decisions on the patient’s behalf needs to consider the impact of SET on the emotional mindset of those patients and if necessary offer adequate further support for their decision at the clinic level. Another post (and the final one I will mention as no other topics were raised) was one from a mother of three-year-old twin boys. She was due to undergo an SET cycle upon the insistence of her consultant. Her twin pregnancy involved severe complications “ bleeding till 21 weeks, including massive clots and haemorrhaging, extreme "morning" sickness until the day I gave birth, pre-eclampsia, obstetric cholestasis, primary post partum haemorrhage at birth, secondary post partum haemorrhage 2 weeks later, requiring surgery and so on! I was hospitalised 13 times in total”. However she stated that without the insistence of the consultant she still wouldn’t opt for SET because of the low chances of success that IVF treatments have overall.

The last UK based fertility website that I analysed was “IVF-Infertility.com”. This site was less busy than both of the other sites. This site, like the others, offered valuable support for patients undergoing similar fertility treatments. Parents also lent each other support, especially parents of multiples. Again, I searched information regarding multiple births and single embryo transfer. Posts were dated from 2002 to 2011. All topics discussed on this site were identical to other sites. However, a few new perspectives are worth mentioning.

One post brought up the topic of selective reduction. She said that her clinic offered a form that insisted parents agreeing to do a selective reduction if the pregnancy resulted in a multiple pregnancy. She said “selective reduction is always an option to ensure only having one at a time if you think that is something you would be able to do. Personally I couldn't do that, so I did not sign the form”. Her opinion reflects other attitudes displayed by patients on other similar sites. This suggests that selective reduction is not a viable tool to curb the clinic's multiple rate. However, it was interesting that this clinic offered such a form for those opting not to do SET.

The site also offered a clinician's attitude towards single embryos transfer. This clinician said “I've been pushing for more SET at my clinic, partly because we have a good freezing program”. She also referred to the discovery of the ‘vanishing twin’ effect, in which even the early failure of a sibling embryo has negative effects on the remaining embryo(s). This clinician felt that SET meant fewer complications and fewer miscarriages for patients. However her post went on to say that “the patients don't seem to want it. They seem to want to maximise their chances in each transfer, rather than in each retrieval (including subsequent fresh and/or FETs). I can't agree, but I'm not the patient.” Again, this comment is perhaps a reflection of the emotional, physical and financial impact of subsequent cycles, regardless of whether they are fresh or frozen.

One post brought valuable attention to the fact that SET cannot totally rule out multiple pregnancies. She said that “I really thought we were effectively

eliminating the possibility of multiples because of the quality, or lack there of, of one of the blasts; however, I must tell you that we are now expecting identical twins. To further my story, we were initially expecting identical triplets, which was really scary from a financial and health perspective. We had one of our embryos split twice, so you never really know what might happen". It has been observed that identical twins are a phenomenon that may be associated with blastocyst transfer. It is speculated that selecting large and healthy embryos may be consistent with selecting those more likely to combust and form two (Payne 1998).

An over 40's perspective on the proposed HFEA legislation to reduce SET in 2009 caught my attention. The lady who wrote it was concerned that widespread SET would mean longer waiting times in clinics. Clinics would be conducting more cycles to achieve a live pregnancy than with double embryo transfer. This would have particular significance to older IVF candidates whose fertility would be declining rapidly. She states, on her post, that widespread SET "would mean that so many wonderful UK ladies may need more IVF treatments to achieve pregnancy. We already know how stressful, emotional, and costly this can be...not to mention the time off work that working ladies will need for all the scans and bloodwork. It may also delay treatment for those who are on waiting lists in the UK. What about the over 40 ladies that need to achieve pregnancy as soon as possible for better chances of a healthy full term baby". Her post emphasises the problems that repeating cycles can bring on patients. She was the first commenter to point out problems that SET may bring in terms of more waiting for appointments at clinics. The time needed to repeat frozen cycles could result in longer waiting times for appointments at UK clinics. Infertility Network UK carried out an online 'fertility tourism' survey and found that 76 percent of respondents would consider travelling abroad for treatment. Of those, 70.5 percent said it was because of shorter waiting times than in the UK, 69.5 percent gave the cost of treatment as a reason, and 61 percent pointed to the success rates of conception in clinics abroad (Infertility Network UK 2008). From this survey it appears evident that patients are already very concerned with waiting for appointments.

## 8.2 Analysis of Support Sites attached to Fertility Clinics

After looking at the public Internet sites, I moved on to analyse the site that was connected to IVF clinics in the UK. Surprisingly only one site in the UK offers such a support service to patients. This belongs to a large clinic that offers multiple sites for IVF treatment at eleven clinics around the UK. The site exists to support patients from all locations although some areas of the site are clinic specific. Postings on this site dated from 2004 until January 2012. The topics posted on this site did not vary widely from those on the public sites. The only differences I observed were that postings could often be more clinic specific. For example, one post discussed the virtues of the counsellor at the clinic and posts described experiences with this particular counsellor. Another post discussed the experience they had with particular consultants at the clinic. The posts were also able to be area specific. Patients were able to discuss facts about local NHS funding and recommend a particular chemist or a therapist for acupuncture or other supportive treatments within the vicinity of the clinic. Also, the clinic itself used the board for notices. These included notices to advertise the availability of identified vitrified, imported eggs from the United States. These were offered at a shorter wait than identifiable UK donor eggs. Another notice gave instructions on how to access NHS funded treatment through visiting one's G.P.

Most of the postings on this site discussed methods of extra support surrounding clinic treatment. Posts covered topics such as how to administer injections, diet, how to juggle IVF and work, travelling during treatment, supplements and a whole range of alternative therapies including acupuncture, reiki and reflexology. However, there were numerous postings to discuss single embryo transfer. Lots of patients considering the treatment were eager to hear from other patients whereby such treatment had been successful and postings were encouraging in response to these requests. On the whole, patients were more positive about single embryo transfer when they already had one live success from a previous IVF cycle. Also more recent postings (those recorded in the last two years) responded with more patients' experience of SET as the treatment has become more prolific and

subsequently more patients are able to comment on success stories resulting from their SET experience.

When I looked at postings around the time of 2007, when the HFEA wanted to introduce policy to promote SET, many visitors to this site said that they had participated in the HFEA public consultation. Attitudes towards SET on this site were similar to attitudes on other sites in that the majority of comments were negative about SET. Many patients felt that they would go abroad to seek treatment to avoid having restrictions on the number of embryos they could choose to be transferred. Other commenters felt that the HFEA had given unjustified concern only to the welfare of the unborn child and not to the welfare of the mother. It was felt that consideration was not adequately given to the emotional, financial and physical strain of repeating IVF cycles to facilitate SET. Some posts cited abortion legislation as being concerned with the welfare of the mother and not the child. One post summarised many patients' feelings that "that the HFEA does not fully appreciate what a patient has to go through during IVF treatment. The HFEA seems to be quite detached from this". These sentiments echo patient input into the HFEA's consultation in 2007. The HFEA posted the summary of the consultation on their website in a paper titled: Multiple births and single embryo transfer review: evidence base and policy analysis. The HFEA's consultation observed and recorded that "Patients considering or undergoing IVF treatment are clearly desperate to have a child. They are already frustrated that success rates are low in the UK. They do not believe that success rates will stay the same with SET. They reject any policy they see as potentially decreasing further their chance of success, albeit for the better safety of the prospective children. They believe that their needs should equally be taken into account". However the consultation concludes that: "The evidence base linking the practice of multiple embryo transfer and the consequent establishment of pregnancies at significantly greater risk of serious complications is irrefutable. The health benefits to children, the reduction in distress for families and the enormous cost savings for society, through reduction in need for immediate and long term health care for affected children, make an overwhelming case for change in this area of clinical practice" (HFEA: 2007).



Several posts discussed the counselling service available at their clinic. All responses about counselling were positive. One post described how the counsellor enabled her to “download” all of her emotions and feelings regarding the difficult circumstances surrounding various treatment cycles. There were several comments about how IVF had had a negative impact on a patient’s sexual intimacy and counselling had helped to overcome this. Some IVF patients reported that they wished they had used counselling in hindsight, as it would have been helpful whilst undergoing IVF treatment. Many felt that they were still suffering the effects of treatment several years later, particularly where treatment had led to loss or a series of losses.

In addition to specific topics the site was used heavily for general support. If a patient posted details of difficulties or bad or even tragic news other patients were eager to write their support and best wishes. The stress levels suffered by the IVF patients were evident in all the postings. One patient asked, “How does anyone survive this stress?” Each stage of the IVF cycle was dissected and discussed and the site allowed patients to empathise and to give support and sympathy to one another. It was evident through all of the hundreds of posts that I examined on this particular site that, as one patient summarised: “every single stage is a hurdle to overcome”. Many site users commented that the bulletin was the only thing that kept them emotionally strong and able to pursue the vigorous treatment stages. One user summarised this sentiment “the ladies on here are brilliant and are always there for you, you will never feel alone”.

### 8.3 Discussion: Juxtaposition of IVF-user views and practice discourses regarding SET.

Through researching some patient attitudes towards fertility treatment on the Internet it has become clear to me that IVF is not a neutral technology but a value loaded one. It is a process that has different meanings and qualities both for those having direct experience with it as well as for wider society. The benefits and dangers of IVF depend upon the context in which it is employed. Different groups

of people have conflicting hopes and fears about fertility treatment. The social construction of technology perspective developed by Bijker and Pinch appreciates that different social groups have different understandings of technology. The implications of this are that technology does not determine human action, but that rather, human action shapes technology. Consequently it can be argued that the ways a technology is used cannot be understood without understanding how that technology is embedded in its social context (Mackenzie, Wajcman 1992:23).

One key objective of my overall investigation into IVF and multiple births is to 'give voice' to the users of IVF. In this chapter I demonstrate my attempts to do this by reading about the experiences of those who are engaged with IVF technology. I have used on-line forums as my 'field' and in doing so I hope to gain knowledge and perspective related to their experiences. This type of fieldwork may be described as feminist, in so far as my online observations constitute a flexible course of enquiry. This is because, when compared to other methodologies, their 'scientific' orientations tend to obliterate (Williams 1990:254) access to all voices. The women who are using IVF and sharing their experiences online are the counter dominant discourse to practice and policy discourses. Therefore my research is feminist in that I am focusing on the IVF experiences of those who have been traditionally marginalised. In doing so I can reveal how inequalities are reflected in asymmetrical relationships in the IVF clinics. My goal of social inquiry is a solution through political action in the form of social policy within an ideology of emancipation. Although these women share the common experience of the clinical environment their interaction with it comes from highly individualised standpoints and contexts and the on-line narratives that I read demonstrate this. I then use this knowledge to support my commitment to a particular position regarding public policy. In doing this any information I seek is not just knowledge 'about' patient perspective but also knowledge 'for' the social change that I propose. My commitment is for change in the social world that defines embryo transfer policy. Liz Stanley summarises this as a particular feminist commitment to "change the world, not to study it" (Stanley 1990:15). In doing this I am attempting to close the divide between patient and social policy discourse.

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I have attempted to locate patient discourse within Foucault's ideas of language and discourses as a key for any patient to explore and interpret the reality of their experience of the IVF clinical process. My assumption is that patient identities are not fixed but fluid and fragmented. The identity of any patient and their relationship with the clinical process and with the disease that is infertility changes according to their position within the clinical process as well as their social position outside of the clinic. This means that any patient response to any aspect of the IVF treatment is always in process and unfinished. A Foucauldian theoretical perspective is that discourse during the treatment process can encourage the patient to examine their relationship with their status as an infertile individual. If encouraged and promoted within the infertility clinic, counselling may be a container to unravel the response that is unique to any one individual and encourage a higher level of patient status by allowing for the development of individual agency and autonomy within processes of treatment in the clinic.

Beauchamp and Childress define autonomy as 'a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself. A person's autonomy is his or her independence, self-reliance, and self-contained ability to decide' (Beauchamp and Childress 2013: 56). Counselling may act as a vehicle to encourage and protect patient autonomy because patients are involved in discussion, debate and information surrounding SET which can help them to be involved in their own medical care and make rational choice regarding such care. This exchange of discourse surrounding SET may furthermore maintain relations between clinicians and patients. In allowing any patient to scrutinise the medical service of which they are a part may produce benefits for the service as a whole. This can encompass the whole clinic as clinicians and clinic staff are liable to be more open to self-scrutiny. Counselling may, in this capacity, carry some of the advantages of informed consent because it promotes individual thought and initiative (Beauchamp and Childress 2013:64) within the highly medicalised clinical process. The counsellor will do this by giving the IVF patient sufficient information to make an informed choice and provide them with all possibly relevant knowledge regarding their treatment and give them ample opportunity to discuss and understand such

information.

The counselling space may allow for a period of reflexivity and permits discussion that can be separated from the patient/clinician relationship and the dialogues of power that are inherent in these roles. In the space offered for counselling the patients can talk about their own unique feelings, circumstances, opinions, values and desires. Within the context of the counselling forum a plan can be made with regard to embarking on SET that is compliant with clinic policy and is patient orientated.

The assumption underlying this research is that the promotion of the legitimacy of governmental implementation of restrictive public policy to promote health. In this way public policy validly intervenes in the lives of autonomous persons. In this regard my research is socially situated, adopts a clear premise and is 'part of the social world it studies and does not operate outside that world, in some pure realm of autonomy' (Hamersley 1999:3). As a researcher I am operating in a particular context motivated by a desire to position myself with a very specific attitude towards the issue that I am researching. However, the primary goal of the research is to investigate the issue of SET and discover knowledge about the topic. My secondary goal is the promotion of health policy and this goal is viewed separately from the process of the gathering of knowledge.

The postings by patients on the sites that I investigated showed resistance to public health policy to decrease multiple births that result from IVF by encouraging single embryo transfer. From my investigation it was evident that many patients were experiencing intense suffering. Their goal was to conceive a child and it was widely perceived and believed that single embryo transfer was a barrier to that goal. Inhorn's summary of this type of attitude during her research was that patients were "willing to do anything, even risking their own lives in the pursuit of risky remedies in their efforts to conceive" (Inhorn, 2003:1842). Patients may not be able to make accurate judgments about the information available to them during the IVF process. A woman may be unaware of the full implications of a multiple pregnancy when desiring to undergo a procedure that would involve transferring

more than one embryo into their uterus during IVF treatment. Providing counselling as a routine support service for patients at IVF clinics could provide a forum to discuss issues surrounding single embryo transfer and multiple births in addition to providing general support for what is an extremely stressful course of treatment. Counselling provides a forum for discussion, judgment and autonomy for the patient in what is otherwise a rigid, medicated and sterile clinic procedure. Franklin warns us of the dangers of this type of medicine and how it shapes the IVF technology itself: “prescriptive technologies eliminate the occasions for decision making and judgment in general and especially for making principled decisions. Any goal of the technology is incorporated a priori in the design and is not negotiable” (Franklin 1989:25).

Many patients voiced concern that implementing single embryo transfer would mean more visits to the clinic and felt that this would further increase the stress and anxiety that is induced by the procedure and its invasion in the patient’s lifestyle. Increased access to counselling may help some patients to manage the extra visits that may be necessary to achieve pregnancy. Patients may find counselling a forum to discuss financial and employment difficulties surrounding treatment as well as issues such as the way in which IVF as a treatment process may both internalise the role of motherhood and simultaneously alienate a patient from it.

Lastly, patients’ concerns about single embryo transfer were clearly intertwined with patients’ financial concerns. It has been demonstrated that in the US, comprehensive insurance mandates were associated with greater utilisation of ART and lower rates of births per cycle and multiple births per ART birth (Henne and Bundorf 2008). There is a huge personal cost involved for many to achieve pregnancy in this way and this socio-economically and racially profiles IVF. It does this by pricing those with moderate means out of the infertility ‘market’. One study sought to assess primary care physicians’ awareness of the infertility risk associated with race, age, and education, and to elicit their clinical management recommendations for a hypothetical patient. They found that these doctors appeared not be sufficiently aware of the infertility risk of African American women

and women with lower socioeconomic status to ensure that women in need of services are identified (Ceballo *et al.* 2010). Another study, also from the US suggests that eSET may also be racially profiled. The study recorded the number of embryos transferred as adjusted odds ratios (AORs) from clinic based data over a 2-year period. Researchers found that, compared with white women, eSET was used more with Asian (AOR 1.52) and less with Black or Hispanic women (AOR 0.73 and 0.67, respectively) (Luke *et al.* 2010). Social research should acknowledge these socially specific racisms in the development of equitable public policy.

The limited treatment available to patients on the NHS could be expanded to accommodate SET by including frozen cycles and blastocyst culture development within the boundaries of what constitutes a funded cycle. There would be a small increase in NHS costing for fertility treatments but large NHS savings for the operation of neonatal care for those babies who are born at low birth weight as a result of being a multiple gestation. Additionally many patients stated that their reason for desiring a multiple gestation was because the NHS would fund no further cycles and therefore a twin pregnancy insured a sibling for their child. This may be considered as a funding consideration to implement and endorse the widespread adoption of SET alongside an emphasis on provision of counselling to provide a forum to discuss SET and alleviate stress factors associated with increased repeated IVF cycles that result from the adoption of this technique.

## **CHAPTER NINE**

### **SUMMARY AND POLICY RECOMMENDATIONS: SUGGESTIONS AND COMMENTS ABOUT CLINICAL PRACTICE ARISING FROM DISCUSSION IN INTERVIEWS WITH IVF COUNSELLORS**

#### **9.1 Summary**

This study is a contribution to policy discussions regarding IVF public health policy in the UK. My special area of interest is the impact that IVF is having on the multiple birth rate and the health of those born. A policy response to the increase in IVF multiple births is to increase support and discussion forums in the IVF clinic. This may be successful if implemented in the form of increased counselling provision within UK infertility clinics. The counsellor could offer each patient a space in the clinic discuss multiple births and promote single embryo transfer. In this way counselling may be a forum to more fully discuss SET as a treatment option with the patient.

As one possible solution to the problem of IVF multiple births I have set out to recommend the establishment of a policy to reduce multiple gestations. This investigation proposes that patient centred techniques to promote single births should be introduced to clinics in the UK alongside single embryo transfer and other tools to assist clinical judgment. Patients in the UK are currently largely resistant to the idea of single embryo transfer and involving them more fully in this decision through the use of counselling and other support can clarify their concerns. Support mechanisms within the clinic may furthermore make the clinic experience more emotionally manageable and may increase pregnancy rates.

Figures available from the HFEA indicate that in 2008 15, 082 children were born as a result of in vitro fertilisation techniques. Approximately 4000 of these children were a multiple birth (HFEA 2008). Half of these multiple births, or roughly 2000

children would need neonatal care and suffer long-term health issues as a result of being a multiple. The other 2000 children would be of a low birth rate but develop without health complications (Ericson *et al.* 2002). Since the start of this project the UK has taken steps to decrease multiples born from IVF, and in 2009 a reduction policy in embryo transfer for clinics arrived. This means that my study assumed the tasks of recommendations to implement this policy rather than recommendations to establish such a policy, which was my intention at the start of this investigation in 2004. My investigation sought to discover connections between patient support and multiple birth reduction policy at a clinic level. I feel that patient support can act as a forum to educate and inform patients about multiple gestations and also improve the success rate of single embryo fertility treatments by decreasing stress and distress. Good patient support gives the individual the deserved full information and help with IVF, which is physically and emotionally difficult and still often unsuccessful.

At the start of my research project I looked at IVF multiple birth rates in North America and Europe so that I could position the UK in an international context. Here I identified a clear contrast between countries where there is no legislation to govern multiple births to where SET is actively promoted. The next part of my research took place in Canada where I was a resident at the time. In the role of patient (observer), I interviewed some clinicians at two IVF clinics. I was also privileged to attend many support group meetings at one clinic. Here, I was repeatedly told that lack of information and support during the IVF procedure was a problem, and increased the patient's anxiety. This led me to consider whether patient support may be a tool to implement SET at a clinic level. In the UK fertility clinics have been required by health policy to offer counselling to all patients since 1991. I contacted each clinic in the UK to see what type of support they offered e.g. counselling, support groups, relaxation classes and so on. I then looked at the success rates and single birth rate of each clinic. To gain insight into the services offered to patients to support them through their treatment I interviewed counsellors who worked at clinics throughout the UK. Their insights provided an adequate assessment of the breadth and quality of services available. I then accessed patient opinion about single embryo transfer from patient support sites



targeted at UK residents. These sites gave me access to personal perspective and detailed patient accounts and experiences.

A policy response to the problem of multiple births could be to increase counselling provision in UK clinics. Using the counselling service as a forum for information giving and discussion about multiple births may help to promote elective single embryo transfer. Current, international research by Boivin and colleagues suggests that the discontinuation of IVF treatment was a result of various treatment burdens. Although further research is needed the team recommended that 'treatment burden should be addressed by better care, organisation and support for patients' (Boivin 2012:652). Patients were seen to be in need of better information and opportunities to discuss value and worries involved in the treatment process. Patient support could be an important tool to promote SET because services such as counselling and support groups may act as a forum to discuss and inform a patient about the benefits of a single pregnancy. When I met with counsellors at their regional forum it was suggested that counsellors could reinforce the need to redesign the IVF procedure. They felt it was important to present the prospect of elective single embryo transfer as a package.

A 2010 study (Mc Leron *et al.* 2010) demonstrates that single fresh embryo transfer followed by single frozen embryo transfer would offer equal success to a double embryo transfer but eliminate all health risks associated with multiple births. This important UK study has suggested elective single embryo transfer (eSET) during IVF may improve chances of delivering a healthy baby compared to DET, although women receiving DET are more likely to become pregnant in the first place. The team led by researchers from the University of Aberdeen collected data from 1,367 women who had undergone IVF. Of these women, 683 used eSET and 684 DET. The findings showed that the chances of a full-term single birth (over 37 weeks) following eSET were almost five-times higher than those following DET. It also found eSET to reduce the risk of premature births, with pregnant women being 87 percent more likely to avoid a premature birth before 37 weeks as a result of the implantation method. Furthermore, the likelihood of having a baby of low birth

weight after eSET was one third of the chance following DET. Even though the pregnancy rate following eSET was lower. It was discovered that 27 percent of women undergoing IVF after eSET delivered a healthy baby, compared with 42 percent after DET. This difference was reduced upon implantation of a further frozen single embryo after the initial transfer, giving an increased success rate of 38 percent. The researchers concluded that given the findings of the study, eSET should become the 'default position' in IVF. This study found a similar success rate to an earlier study by Stillman and colleagues. They also discovered that eSET use among good-prognosis patients can significantly reduce twin pregnancies without compromising pregnancy rates. However, this study also analysed payment method upon choice of eSET uptake. They discovered that uptake of eSET was significantly more common among patients with insurance coverage or who were participating in the clinic's Shared Risk money-back guarantee program. Patients are more likely to choose eSET when freed from financial pressures to transfer multiple embryos (Stillman *et al.* 2008).

The counsellors I met with and interviewed from the BICA, all felt it was important to present SET as a package, to convince patients that this would promote a more equitable outcome for themselves and their children. In other words, patients need full information about the process. Single Embryo transfer will likely involve single embryo transfer followed by frozen single embryo transfer. My investigation of patient opinion demonstrates that to be attractive SET should to be endorsed by financial arrangements that encourage rather than prohibit embarking on a slightly longer treatment program. This package could then be coupled with extra support services in the form of counselling and other support which give full disclosure of the process in an attempt to combat any stress and interruption associated with adherence to a more complex and lengthy treatment schedule.

However, it should be acknowledged that current research suggests that single embryo transfer may not be appropriate for women over forty years of age. Findings provide some support for the transfer of two embryos in women older than 40 years, because the risks of pre-term and low birth weight were lower than those in younger women. Generally women in this age group have lower chances of

falling pregnant, and so were less likely to have a twin pregnancy after the implantation of two embryos (Lawlor 2012).

My on-line investigation of patient opinion in the UK suggested that patients desire to transfer as many embryos as possible during any one IVF cycle as they hold the general perception that this will maximise their chances of conception. Counselling sessions may provide a patient with a forum to discuss the increased problems arising out of the practical side-effects of elective single embryo transfer. Extra cycles to incorporate a frozen cycle means for example, more time off work, more visits to the fertility clinic and a potential increase in anxiety levels for the patients. The high anxiety levels that occur between implantation and pregnancy test results will also increase in frequency. Emotional issues may further become amplified, as each patient is likely to spend more time in treatment. The counsellor may help each patient to understand that suffering anxiety and stress is a normal and expected side-effect of treatment. They may help the patients by discussing mechanisms that they can set up to allow themselves to manage the demands that the treatment brings. Also, many studies suggest that support can influence the success of IVF. Patient support in a variety of forms may also help maximise the chances of successful implantation of the single embryo and therefore negate the necessity of implanting multiple embryos.

Feedback to the HFEA from patient surveys about SET suggest that they are influenced in whether or not to take it up and use it as a treatment option by the way that they are informed about it. It was thought to be better to receive such information, consistently, via face-to-face discourse with all the staff at the clinic. Patients also reported the need for a forum to discuss this information, for example, in a support group or counselling setting. This support was considered to be also helpful when faced with making a decision to use SET. When asked, 92% of patients who did not choose SET thought they could increase their chances of getting pregnant and when asked what would have changed their minds 73% said better success rates from SET (HFEA 2010).

The provision of easy-to-access counselling and support groups may therefore act as a forum for patients to discuss the option of SET and the benefits for the patient's health and health of any possible future child born as a result of the treatment. It has been discovered that the longer term infertile patient displays significantly more positive attitudes about the prospect of a multiple gestation than the newly infertile control group (Leiblum *et al.* 1990:pp.197-210). This study demonstrates that evidence relating to multiple pregnancy risks need to be carefully organised around the individual needs of each patient. The counselling forum may provide an exclusive opportunity for such discussion. In 2004 another study confirmed that 20.3% of patients or, one in five women listed a multiple birth as their most desired outcome of infertility treatment. Income slightly influenced this desire with those families on a lower income demonstrating less desire (Ginny *et al.* 2004). Again, this study demonstrates a need to organise SET discussion around individual circumstances. The high incidence of desire for multiples also supports a notion that the incidence of multiple births for IVF patients may be in part patient driven. Therefore, patient education may be an effective strategy to reduce the incidence of twin and higher-order multiple pregnancies.

Many studies support the premise that the provision of support services for IVF patients can improve the outcome of the IVF cycle. Support services could be used in conjunction with SET to improve outcome. Domar found that IVF patients enrolled in a mind/body support program before the start of their cycles significantly increased their chances of pregnancy compared to the control group. It was found that the program had no effect on women who conceived at the first try. However, women who failed at the first attempt and were trying to get pregnant a second time, whilst using the stress management techniques, experienced a 160 per cent greater pregnancy rate than those receiving IVF treatment alone. Evidence from this carefully designed study demonstrates that it is clear that a holistic approach to infertility care leads to better outcomes for patients (Domar 2010).

Earlier, Domar *et al.* confirmed that cognitive behavioural therapy and group support increase IVF success rates (Domar *et al.* 1992). A Turkish study

undertaken by Terzioglu confirms that counselling increased IVF success rates in the study population (Terzioglu 2001). Psychotherapy showed to improved success rates in de Liz and Strauss' study (de Liz and Strauss 2002).

Furthermore, a programme of body-mind therapy undertaken by one group of patients in Lemmen *et al.* study was found to increase pregnancy rates for participants (Lemmen *et al.* 2004). Although there have been no systematic studies in infertile women undergoing IVF, examining other types of support such as education and skills training, relaxation methods, acupuncture, pharmacotherapy or other methods of support. It has been speculated that treatments that decrease psychiatric symptoms and stress in the general population will likely benefit this population.

Stress, depression and anxiety are documented causes of infertility. Lukse found levels of these to be high before, during and after IVF treatment and concluded that therapeutic counselling would be more effective if commenced before treatment (Lukse 1999). Domar found that depression levels differed according to the extent of treatment (Domar 1992). Boivin and Theiring confirmed this. They found that depression was curvilinear according to the time a patient was in treatment. Women 2-3 years into treatment were found to have higher levels of depression than those in treatment for 6 years or longer (Boivin 1995, Theiring 1993). IVF support could take into account that patients in this moderate level of treatment cohort may be in greater need of support.

My interviews with fertility counsellor teams working out of UK fertility clinics indicated that there was a vast gap between actual and potential support services for patients at these clinics. Most counsellors told me that currently, most discussion surrounding SET was done with the clinician. Their contact with patients was often minimal and mostly surrounded disclosure formalities related to donor gametes. The counsellors that I spoke to were of the opinion that all the clinics they worked at had thoroughly undertaken Human Fertilisation and Embryology Authority policy mandates. Nearly all counsellors felt that the clinic's clinicians

were attending to the multiple birth issue. Data recently collected by the HFEA contradict this as most UK clinics struggled to achieve the HFEA's targets of 15% last year (HFEA 2012). This is outlined in more detail in Chapter 2.

All counsellors felt that support services could improve at the clinic they worked at to support patients through a treatment which "was probably going to be the most stressful time of their lives". My research found that support services were marginalised in the context of the fertility clinic because 1) the intentions and interests of the clinic were antithetical to the interests of the counselling and support services. Transparency and exploration about the product may lead to a failure to embark on treatment or a decision to terminate it. 2) Fertility medicine is available in the UK in a dualistic capacity. The Government offers limited provision per patient. Private treatment is unlimited. The state interest in provision of support was more apparent in the government-funded service. Hence in some ways the private provision of the service works against state interests. My investigation concluded with some suggestions for how support services could be improved at a clinic level. These suggestions follow:

## **POLICY RECOMMENDATIONS: SUGGESTIONS AND COMMENTS ABOUT CLINICAL PRACTICE ARISING FROM DISCUSSION IN INTERVIEWS WITH IVF COUNSELLORS**

### **9.2 Counselling should be incorporated into the culture of the clinic**

All of the counsellors that I spoke to were of the opinion that the counselling service within their clinic could be improved and expanded. For this to be successful the counselling service needs to be accepted and promoted by all the staff as a group. This depends upon communication between co-workers and team efforts promote patient care. This will be influenced by the work ethic of staff, individual staff attitudes towards counselling and respect for the counselling service offered and the patient they are offering treatment to. For counselling to be the best

service for all patients it needs to be integrated into the culture of the clinic and not just offered as an additional grafted on facility that patient have to seek out to use. This would entail all clinic staff promoting the counselling service to every patient in a face-to-face verbal fashion.

Infertility counsellors are trained to be of valuable assistance to all clinic staff. If the counselling service is fully integrated into the clinic then counsellors will be in an accessible position to educate all staff in patient communication skills. This may include skills necessary to promote SET. Feedback from patients to counsellors regarding SET may be imparted to staff members so that policy pertaining to SET may be recommended in a way that takes into consideration the psychological needs of any patient.

Staff may need to be guided about the mechanisms of the counselling service and the type of help that it available to patient. The service must also be physically integrated into the clinic environment. If counselling is to become naturalised in the same way that Cussins observed other mechanisms of the clinic functioning (Cussins 1999), it is necessary to be prioritised as a valuable resource to draw on at any level of clinic treatment. This may be compounded by financial obligations, which may create a conflict between productivity and care. It also may be contradictory to other clinic protocols relating to productivity because the production of narratives about the treatment could stimulate less demand for the service as any patient's relationship with the services may gain transparency. Discussion in the interviews with UK infertility counsellors drew attention to some processes that may promote the incorporation of counselling into clinic practice.

### 9.2.1 Attending Meetings

All counsellors that I spoke with, thought that they should be included in and invited to clinic meetings. These meetings are useful further opportunities to see and talk to the other staff at the clinic. They also give the counsellor opportunity to discuss feedback about the clinic, its service and staff that might have been raised in counselling sessions. The counsellors are in a unique position to educate the

clinicians and other staff about concerns that patients may encounter during the treatment process. At regular staff meetings clinic policy can also be passed down to counsellors so they are fully informed about all procedures when offering support.

### 9.2.2 Audits and Keeping of Records and Feedback

Feedback was thought to be very important by all the counsellors that I spoke to. Each patient at a counselling session could be given a feedback sheet that gives them the opportunity to address issues that they may have with fertility treatment and counselling. A stamped addressed envelope should be given if the patient wishes to take the feedback sheet away. The feedback sheet gives a forum for both the counsellor and the clinic to ask a whole range of questions. There should also be space for the patient to give his or her own comments. The counsellor will then know if there is something that they can make sure is covered in other sessions with other people. If there is an issue about the clinic then the counsellor can agree with the client if they want the issue brought forward. If so this can be done anonymously. Counsellors can use these feedback sheets to make improvements in the counselling service. Feedback regarding the clinic can be brought to meetings at the consent of the patient. To provide a good service the counsellor needs to be aware of all clinic policies. Counsellors should have access to all statistics about patient intake and number of cycles each patient is undergoing. This can assist in understanding the amount of counselling being used at the clinic, by whom and when. Counsellors can audit whether sufficient counselling hours are being funded at any one clinic. Currently BICA has standard templates for audits that are required to be filled by counsellors. These statistics should be organised in conjunction with statistics kept by the clinic. Four counsellors with whom I spoke felt that there was a disconnection between data kept by themselves and the data of the clinic as a whole. However, when I attended the BICA regional forum in 2011, I was informed of a new system introduced by the association to keep increased accuracy in clinic records. Counsellors should soon be expected to record the number of first counselling patients or donors compared to the number of treatment cycles. This figure was



thought to be clear and comparable across clinics.

### 9.2.3 Ethics Meetings

Two counsellors suggested that running a regular 'Reproductive Ethics' meeting had become a useful part of clinical practice at their workplace. They thought that this can give the opportunity for the team to meet and discuss ethical issues surrounding treatment and act as a forum for the counsellor to voice concerns and issues that may be raised in sessions. They may be able to raise concerns about the needs of particular clients and act as a patient advocate when the clinic is making ethical decisions. An example of this on a clinic level would be whether or not the clinic is to offer egg sharing. An example on a patient level may be whether or not to offer IVF where a daughter intends to donate eggs to her mother for her to have a child with a new partner or other arrangements that involve donation or surrogacy amongst close relatives. In such discussions, the counsellor is able to offer valuable insight to the clinic as a result of their contact with many patients. Issues regarding single embryo transfer can be discussed at such a forum. However, not all counsellors thought this to be a good idea. If a counsellor is perceived as a moral authority within the team it gives the perception of counselling to be about assessment and this will be conveyed to patients. For counselling to be effective, the counsellor must offer the patient a space within the clinic environment where they are comfortable to talk about their personal lives without judgement. Counsellors are not ethicists.

### 9.2.4 Staff Training

The counsellor's role as part of the staff team should be emphasised in all clinics as counsellors have skills and resources to offer all staff and not just patients. Counsellors are trained communicators and in this capacity can help to provide other staff members with skills. All clinic staff need to be able to clearly impart

information and facilitate discussion about every aspect of the treatment process. Counselling can be part of the staff training at the clinic. This makes counselling a priority for all the staff as it increases their general awareness of the service. Counsellors can give each member of staff an information session about the service and talk to staff about how to discuss the service with all patients. Furthermore, counsellors can give training to staff in issues such as anxiety management and grief management. Workshops can be run for staff for things such as 'breaking bad news skills' and 'managing disheartened patients'. All staff should understand how the stress and anxiety that is involved with undergoing fertility treatment makes patients behave. Attention can be given to the gender divide that counsellors frequently identified in staff. Currently, more patients appear to be coming to counselling through the female clinicians. If training is done with counsellors on all staff levels then all staff are better equipped to support the patient as a team. If the management of the patient's feelings are generally incorporated into all staff practice then clinicians and other staff are less likely to send a patient to "tip-toe off site to deal with it" (quote from one of the counsellors that I interviewed) and the image of counselling and support can be incorporated into the infrastructure of the clinic. This will subsequently improve the patient's perception of counselling as a positive service, available to support them through their time at the clinic.

#### 9.2.5 Cards

Small cards (like business cards) promoting counselling services could be left in all the rooms all over the clinic. These should be attractive to look at and small so that they are easily put in a patient's wallet or handbag. They would serve as a reminder to patients so they can think about the card at a time when they are distressed and they might not think about or remember the counselling service. The cards may also offer a more constant reminder of the availability of the counselling service when a patient is in any room in the clinic. The cards can remind both the member(s) of staff present and the patient themselves. The card, when scattered everywhere in the clinic could serve to prompt everybody's

memory.

### **9.3 Counsellors' reports of patients' perceptions of counselling: changing these perceptions.**

Counsellors told me of the importance of their service as a support mechanism during a difficult time. One counsellor told me of the benefits of “reaching out to folks who are going through something which is probably going to be the most stressful time of their lives”. Discussion surrounding infertility focuses upon the most fundamental and important issues in people’s lives.

With the exception of one, every counsellor I spoke with was of the opinion that the counselling service could be improved and used more, within the unit where they worked. Many counsellors told me that they thought they were giving the “bare minimum”. It is considered beneficial for a patient to discuss his or her predicament with somebody who does not have an interest in it, such as a potential grandparent. People derive enormous benefits from just being able to talk. It was reported that many patients were extremely grateful to just be allowed the opportunity to feel “like this” and be assured that the counsellor “had seen somebody like me before”.

#### **9.3.1 Promoting counselling as a service within the clinic**

Counselling can carry stigma and negative connotations. This means that counselling needs to be promoted as a simple normative experience. It should be promoted as being an easy way that any patient may be helped during their time at any clinic. All staff at the clinic on all levels need to be trained in getting the message across to all patients as to the value of counselling and why it is important for them. Counsellors can give staff individual training to inform them

about the function of the service and explain ways to approach and promote counselling when with a patient. Counselling needs to be encouraged as a valuable service by all clinic staff employees and explained as to how it could benefit each individual patient. Each staff member will then be in a position to strongly advise a patient that it would be useful to go to a counsellor to discuss what they might expect to go through emotionally and what resources they may set up to help themselves.

Further ways of promoting counselling can be through open evenings and days held at the clinic for potential patients. Counsellors can be a part of the team that are meeting patients to discuss the services at the clinic and may give information talks about the type of support they can offer.

Three of the counsellors I interviewed suggested that clinics could also stop calling counselling “counselling” and offer the service as “Treatment Support” or “IVF Support Service”. Literature could be changed in the clinic to reflect new titles and although emphasis could remain on emotional support for patients during a time of hardship. As a result of this any stigma associated with the awkward word counselling may be diminished. However, not all counsellors were supportive of this idea. Counsellors have a unique professional identity and changing the name of their service, even at a clinic level only can have implications for the service.

In promoting the counselling service at a clinic level, the clinic team should acknowledge the gender division labour that is apparent within the treatment process. This has been extensively documented by Karen Throsby (2004). Males are often left isolated without any support resources during treatment as they cope by adherence to cultural expectations of masculinity. These masculine expectations are central to cultural ideologies that support the assumption that biological performance and reproduction is central to personhood. Adopting a masculine mask can be a coping mechanism for the emotions that arise from the collapse of such identification. A strong emotion that could be apparent under these circumstances could be shame. By deliberately appearing controlled and impassive a man may be able to superficially circumvent these emotions.

Counselling may be viewed by the male partner as a threat to this personal mechanism of coping with profound distress and consequently be rejected as a forum for support and discourse. Counselling services therefore need to be extra attentive of these sometimes-subtle gender inequalities and male partners should be actively encouraged to participate in services through face-to-face and documented information about the counselling service. Through counselling the responsibility of treatment may be opened in discourse and shared more equitably. In this way both men and women may learn to exert agency over their very different involvements with the clinical IVF process. Regardless of their own fertility status, men may be deeply distressed by their inability to solve the problem of infertility quickly (Nachtigall *et al.* 1992). This response is reflective of cultural dialogues surrounding the male in the role of a supportive (marital) partner that differ from those surrounding male infertility.

### 9.3.2 Confidentiality

Three of the counsellors I spoke with suggested that the confidentiality aspect of counselling could be further promoted at the clinic level. Because of the legal requirement to take into account the welfare of any child born by fertility treatments some counsellors at some clinics feel that the client's fear of being judged as fit for parenthood during counselling sessions has real basis. These counsellors were of the opinion that this prohibits many patients from attending counselling sessions. Confidentiality needs to be clearly asserted around clinic counselling policy. Another professional, such as a social worker such as could be called upon to take on social assessment of suitability for parenthood if it is deemed necessary for any patient undergoing treatment. Foucault believed that engagement in a certain type of discourse makes it possible for the removal of power from the clinical staff and hand it over to the patient (see chapter 5). For this to succeed a value neutral site should be provided free from judgment and the types of patient categorisation apparent elsewhere in the clinic environment. Categorisation is not limited to

inferences about prospective child welfare. Clinical level judgements can be made about patients' age, weight, marital status, financial status and so on.

#### 9.4 The physical environment of the clinic

Social areas for staff to meet can help counselling staff to integrate more fully into the 'culture' of the clinic. A communal kitchen is a good place for staff to meet each other and the counsellor so they are aware of the counsellor's presence and know them on a personal level. A coffee machine can even be a place for networking and "having a natter with people".

Photographs of babies reflecting the clinic's "successes" were mentioned by four counsellors to be disturbing to some patients. Multiple births are very often celebrated with a beaming consultant in these photographs. Without intentionally doing so, these images actually promote multiple births. Having such photographs in a prominent position in the waiting room will normalise the multiple gestation as a product of treatment and stimulate desire for such an outcome for those patients who are trying to conceive. This is seen as indelicate due to the high failure rate still associated with IVF. Photographs could be held in albums in one section of the waiting room.

All counsellors were of the opinion that it is preferable to have their own room within the setting of the clinic. This can improve the quality of the service offered to patients by offering the correct environment to talk. Having specific counselling rooms provides more comfort for the patient. It also elevates the status of the service within the clinical setting and sends a message to patients and staff members that counselling is important and of value that equals other procedures within the walls of the clinic. Furthermore, it allows counsellors to keep paperwork and information for patients at hand, therefore avoiding a 'moving office'. Currently many counsellors did not have their own room and were in clinical settings where they were being frequently disturbed.

Those who wish to use off-site services should then be given a referral by staff. This was deemed particularly important for those patients who wanted to utilise counselling services after they had finished fertility treatment because it is thought to be difficult for them to return to the clinical setting. Other patients simply feel awkward sitting in the waiting room for counselling and don't want other patients or other staff in the clinic to know they are using the counselling service. Offering an off-site service resolves much of the social stigma these patients perceive.

The provision of a permanent comfortable and pleasing space for patients to meet with counsellors is important. In order for any patient to engage freely in discourse they must be able to feel they can detach from what Cussins refers to as the routinisation of the clinic procedures (Cussins 1996). This refers to local knowledge used in conjunction with the technologies such as blood tests, pregnancy tests and ultrasounds. These local practices determine the normal environment and serve to naturalise the technology. So that the patient can discuss treatment and their experiences with it freely all local practices should be absent. In this way the patients' body can be free of the clinical gaze (Armstrong 1984). Foucault interprets this gaze as unique to the context in which it is seen. Therefore for the patient to depart from conceptualisation as an infertile subject the patient needs to detach from the instruments of analysis. Consequently, in a situation where an infertility counsellor is required to hold sessions in clinical rooms that may be not in use temporarily in a clinic the environment offered for discourse prohibits this type of detachment.

### 9.5 Counselling as a mandatory service

A minority of the counsellors (three in total) that I spoke to, thought that mandatory counselling for all patients would be a positive thing. Those that thought it would be a good idea said that it would give every patient a chance to explore their thoughts and feelings about the treatment and the situation that they are in with regards to their infertility. Couples often have two different agendas and are often not listening to one another during difficult circumstances. Mandatory counselling

would give these couples a way that they could start the treatment process as a team. Studies suggest that patients find their experience of counselling to be positive regardless of whether it is voluntary (Stewart *et al.* 1992) or mandatory (Connolly *et al.* 1993).

Eight of the twelve counsellors that I interviewed thought that this was not necessary. One counsellor verbalised this as it being “not appropriate to make it more than a well-encouraged offer”. Currently implications counselling is compulsory in clinics. I was told that if support or therapeutic counselling is to be truly successful, then it needs to be conducted with patients who really want to be there. However it should be considered that multiple births do, however, fall into the category of Implications Counselling because they are implications of transfer of more than one embryo.

Many counsellors felt voluntary attendance worked because IVF is a busy and stressful process, as many appointments need to be met. However the counsellors all thought that all staff at the clinic should promote and discuss how counselling may be of help to the couple undergoing treatment. This should be done at all stages of the treatment with all staff. It is important to do this as many counsellors say at the clinic they work, staff promote the service only when a patient is “not coping”. This enforces the stereotype that counselling is only for those with problems and that seeing a counsellor is not consistent with being healthy.

Research confirms that stress and anxiety levels are constant in IVF patients before, during and after IVF treatment (Lukse and Vacc 1999). However, current evidence gathered from fertility counsellors during interviews and through discussion at the regional forum indicates that extremely few patients voluntarily seek out counselling due to a myriad of barriers (discussed in chapter 7). If they do come to see a counsellor voluntarily, it is likely to be after several failed cycles. An informal session with every patient prior to proceeding with IVF treatment may help to diminish some of these barriers and serve to eliminate any preconceived stigma and fear a patient may associate with counselling. In the UK, Professor



Slade has confirmed this in 2 studies (Slade 1997,2007). She found to very high anxiety and confusion before and during initial IVF cycles in UK fertility clinics. The studies indicate the need for better pre-treatment information. Anxiety levels were also higher after embryo replacement increasing with failure of pregnancy and decreasing with success. The studies recommended psychological support services for patients that recognised anxiety at intake and after failure of IVF. It was thought that high levels of confusion and bewilderment found during the initial cycle may indicate the need for better pre-treatment information.

This was consistent with findings that I discovered through conversations with IVF patients at support groups in Canada (see chapter 3). It also supports a recommendation that would include a counselling/information session for every patient at the time of their initiation into the fertility treatment. Research has demonstrated that services must recognise the presence of high anxiety at intake and provide psychological care for those identified as particularly distressed. Emotional difficulties after failure of IVF treatment can be considered to be iatrogenic effects, and psychological services should be provided to minimise any negative psychological consequences of treatment (Slade 1997). Many other research studies also lend credence to the proposition of introducing counselling to every couple as a support mechanism before treatment begins. Upon presenting for IVF many stressors are identified than are not apparent in fertile controls such as depression, anxiety, confusion, low self esteem, marital strain, gendered division of response to infertility (Hynes *et al.* 1992, Verhaak *et al.* 2005, Bayley *et al.* 2009). Although it is likely that brief therapy will not offer most clients an adequate opportunity to alter their basic attachment patterns, a more realistic aim in short-term work may be to help the client make connections related to how their attachment(s) may be associated with particularly unhelpful coping patterns (Wei *et al.* 2003).

All counsellors were of the opinion that it is important that counselling is offered to every patient and that it is suggested on a regular basis throughout the treatment so that every patient is aware of how it can help them. A letter or brochure

summarising the benefits of counselling can be given to prospective patients at their initial consultation. Five of the twelve counsellors whom I interviewed suggested a 10 minute to half an hour visit, with every patient during the information giving session. Currently in their clinics the nurse typically does this with a new patient to discuss treatment options. This gives the patient a face that is familiar and can personalise the concept of counselling. During this time information can be given to each patient about their counselling options and how counselling can support them through the treatment process. A visit for each patient with a counsellor at the time of their initial embarkment of treatment may serve as an effective time to engage in discussion about elective single embryo transfer. Detailed information about how this implements treatment can be given and facts about SET and how not choosing it can influence treatment, the patient and prospective children. At this time the counsellor can also give detailed information about how the support they offer may help the patient to manage the practical issues surrounding treatment and help to set themselves up with mechanisms to cope with any emotional issues that may arise.

A pre-treatment counselling session would familiarise every patient with the role of the counsellor in the context of their treatment options before they make a decision to embark on any treatment. This session will make access to the counselling service familiar, welcoming and easier to navigate during any future treatment. Any pre-treatment session may clarify full information about the treatment options available including SET. The patient may also be able to discuss the option not to embark on any treatment at all. The counsellor may also assist the patient in accessing skills that may ease navigation of future treatment including how to schedule future visits with the counselling service to clarify these skills and provide further support.

In this way counselling may be routinised (Cussins 1996) in the same fashion that other local practices are in the clinic. This will in time stimulate a naturalisation process, as all patients will expect to undergo counselling as part of the normative treatment experience. For some patients the counselling experience may simply

provide forum for the exchange of information and some opportunity for discussion surrounding the information. For others discourse may be complex and encompass the promotion of an exertion of agency within the treatment process or an exploration of the individual's relationship with the treatment service. The choice of the type engagement with the service lies in the need of the individual.

The doors of access to the service are forced open when the service maintains a mandatory and permanent position within the clinical process.

## CHAPTER TEN

### DISCUSSION

My analysis has provided an opportunity to consider a number of ways in which the organisational structure of patient support in the UK could be improved, and the implications of these possible changes for the IVF industry. It is hoped that any findings from these interviews may help to inform professionals working in the fertility services of the issues that patients are facing and encountering as perceived by counselling professionals at the fertility clinic. This can then be used to provide improved psychological and emotional support to women and couples going through treatment.

An analysis of public policy with regard to IVF involves contemplation on legal, political and moral positions on its proliferation and it is necessary to create a framework that goes beyond any reigning liberal ideology of individual choice. Addelson suggests that the liberal secular humanist ethic that is prolific in our social life has emerged to “emphasise the individual, not simply in valuing and protecting individual people but in taking individual freedom of choice as the centre of ethics. Individuals freely choose values: religion, sexuality, parenthood and family become values for individual choice rather than practices, truths or responsibilities” (Addelson, 1990:5). It is important and valuable to recognise the concept of social choice and acknowledge the reality of economic inequality, male dominance, heterosexual privilege, racism, degradation of the disabled and the uncritical acceptance of scientific rationalism that exists within the fabric of society itself. Designating IVF as a private choice disregards the ways in which systematic and institutionalised privileges or interests operate to limit the interpretation, application and accessibility of individual rights. A fair analysis of public policy needs to look beyond the individual. Just public policy recognises that individual rights must be considered alongside obligations to provide collective well-being and consults the partial perspective of all those affected by it.

This investigation views the infertile woman's enthusiasm for embarking upon the procedure of IVF as a naturalised response. Chapter 5 provides a discussion of how and why; any woman's desire to pursue IVF despite its financial, emotional and physical demands is not a natural individual response to the infertility as a disease but a socially constructed response. Naturalisation is a Foucauldian concept and provides an analysis of how subjects are produced by discourse. IVF has overwhelming powers of social control as a disciplinary technology because it can incite desire and the attachment to social identity. In the case of the institution of the IVF clinic we can observe that new data for the IVF clinic are incorporated into systems already in place and reproduced and changed over time. In this way new techniques such as single embryo transfer can be viewed as a naturalised constructions. The key to the widespread naturalisation of single embryo transfer will be through adequate discourse. Currently it appears from my interviews and investigations that this discourse lies in the hands of the clinicians. For naturalisation to be efficient the discourse needs to be saturated throughout the clinic through all the staff. If this happens information will be more readily at the dispensation of the patient. My proposition is that the counselling team could be crucial to this process. Through naturalisation the practice of single embryo transfer will hence become self-evident, that is, routine, normal and natural.

Counsellors are in a unique position in that they have a private forum for discussion with fertility patients and the counselling session is a conjuncture whereby a patient is able to exert autonomy over the treatment process. Lack of autonomy, lack of information and lack of transparency about treatment procedures were all concerns that I found to be predominant topics of discussion in the support groups that I have visited. Feedback to the HFEA indicates that a patient's readiness to embark on elective single embryo transfer depends on accurate and consistent face-to-face information, administered throughout treatment (HFEA 2010). The counsellors that I interviewed for this investigation were of the opinion that caring for the emotional needs of the patient demands continuity and should not be treated as a single event; it also needs to be endorsed by the clinic as a team and not just by more psychosocially orientated staff members.

Both of the major contributors to sociological research into IVF in UK clinics (Franklin 1990,1998,2006, Throsby 2000, 2002, 2003,2004) have addressed the notion of IVF failure. This notion draws our attention to the fact that language is a powerful tool and all patients should address the failure that is inherent within the IVF process itself before embarking on treatment. Counselling may provide a vehicle for this if it is offered in the right way at the right time to patients engaging in the treatment process. The elusive concept of failure is the very impetus for the use of aggressive multiple embryo transfer techniques that have proven harmful to the women and children that are involved with them. The limitations of the treatment and how this will influence any one patient's interaction with it can be clarified both at the outset and throughout the course of treatment. Additionally, both Franklin and Throsby contribute to the sociological examination of IVF by illuminating the gender stratification inherent in the clinical treatment (Franklin 1990, 1999, Throsby 2002, 2004). This can alienate both parties engaged in treatment from each other and from the treatment process itself. Although confirmation of this did not emerge from my empirical data it may be speculated that, counselling, once again, could serve as a forum to unite gender and provide psychological support for disparities between needs from and experiences of the treatment process that both parents will have.

For this particular work, I have chosen to locate this investigation sociologically within a Foucauldian context. According to Foucault's theory of Biopower, the emergence of government concern with regard to the health and physical well being of the population in general is one of the central objectives of political power. This can be traced back as far as the 18th century (Danaher 2000:90). Foucault is attractive for the purpose of an analysis of IVF because his writings emphasise power as positive and productive rather than negative. His focus is not on the repressive aspects of power. This I believe to be fitting for IVF because its seductiveness can be productive rather than confining, offering women new reproductive choice.

In his portrayal of power relationships in modern societies Foucault has given praise to its fruits," what makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network that runs through the whole social body, much more than a negative instance whose function is repression" (Foucault 1994:61). This is relevant to IVF practice in that participation in the IVF treatment process articulates the constitution of the patients' bodies and their subjectivities surrounding treatment. Each patient is engaged with a complex intersection of relationships of power within the treatment process in the clinic environment. Engagement in the IVF process can be expressed as positive in that it increases the scope of any woman's resources in seeking medical treatment for infertility. More significantly, enrolment in the IVF process itself can be transformative, this is positive because of the opportunity it proffers for the patient to explore the reproductive self. Foucault argues that over time the medical systems provide knowledge systems that we not only can understand but also experience in our bodies (Foucault 1971). From this perspective, medical power may be viewed as a resource where disease can be identified and rectified or given treatment for. Foucault's perspective fits into a wider social constructionist approach in understanding medical knowledge not simply as a given and objective set of facts but as a belief system shaped through social and political relations.

For Foucault, language and discourse are key to social power and social reality. From this perspective, language in this way can be an effective channel of enablement for the IVF patient. Counselling, when offered alongside IVF treatment may be a neutral site for the patient's voice. It may provide any patient and their family members with a forum to regard challenges and demands arising from specific sections of the clinical treatment cycle. Through effective counselling provision, a Foucauldian perspective offers a scenario whereby it is possible to remove certain elements of power from the clinicians involved in the medical procedure that is IVF, and hand control over to the patient. Counselling can be a site whereby patients consider their choices pertaining to SET, and a place to thoroughly investigate it as an equitable treatment option. Counsellors are

equipped with the skills to offer this information and explore a patient's perception of this information.

A policy solution to the problem of multiple births and IVF would be to promote and expand counselling provision in UK infertility clinics. If this happens the counsellor's office may function as a forum for any patient to evaluate their IVF treatment and their current situation in relation to it. Any patient's position in relation to their treatment will be dependent on factors internal to the clinical environment such as time in treatment as well as factors external to it such as influences of immediate and extended family relations. This assumes the Foucauldian ideological position that the patient's identity in relation to the IVF clinic and the disease of infertility is not fixed but fluid and fragmented. The patients' view of their position in the treatment of IVF is always in process and always unfinished. If the clinic offers the appropriate resources then a patient can evaluate their situation in relation to many of the procedures in the clinic, including the opportunity to engage with SET. Other discourses may include the decision to live without children in a social context that prescribes parenthood as a social normality.

For Foucault the IVF patient is constituted of a fragmented self that may have contradictory ideas and experiences and may also be enduring internal conflicts about the treatment process. This contradictory self may be pulled between a number of desires emerging from both the unconscious and the conscious (Henriques *et al.* 1984). These desires may be influenced by factors pertaining to the treatment process itself or may be external to it. The desires can be a product of the patients' emotional investment in others. Different aspects of the self may become dominant at different times of the IVF treatment process. In this Foucauldian understanding of the self and its relationship to treatment it is possible to view the IVF patient as dynamic and contextual rather than static and possibly fraught with ambivalence, irrationality and conflict. In recognising the continual ambivalence of subjectivity it is possible to glimpse some insights into the ways in which IVF patients may be complicit in the medical treatment processes and simultaneously frequently seeking to challenge the processes.



Foucault allows us to consider how the reproductive self becomes created within the narratives of the reproductive technology that the patient enters; in this instance IVF. The highly intrusive nature of IVF means that the process in many ways defines the patient and her body during their engagement with the treatment. During the whole course of any IVF treatment, through a Foucauldian lens, it is possible to view the counsellor as a site for the patient to be independent of this narrative. Proper provision of the counselling service in UK clinics should mean that the counsellor would be familiar to the patient right at the beginning of the treatment process and become a resource to draw upon at any time during what can be an extremely lengthy process of trying to conceive.

For implications counselling to incorporate any clinic's mandate to reduce its multiple birth rate, the counselling could be offered on a mandatory basis or voluntary basis. In its evidence to the House of Commons Science and Technology Committee in 2004, mandatory implications counselling for all recipients of all regulated ART procedures was a priority issue for BICA (Blyth 2008). Currently most counselling in the UK is offered on a voluntary basis. Mandatory counselling sometimes occurs, but only when donor gametes are part of the fertility treatment. This is because the HFEA's current code of practice especially refers to the offer of such counselling in these circumstances and therefore some clinics very often will not proceed without the counselling session having occurred. The infertility counsellors that I interviewed for this investigation told me that clinics are required to check and record, whether or not the offer of counselling was made and whether or not it took place for such patients. However studies suggest that patients find their experience of counselling to be positive regardless of whether it is voluntary (Stewart *et al.* 1992) or mandatory (Connolly *et al.* 1993). These studies suggest that mandatory counselling could be well received in the IVF clinic setting prior to embarking on treatment.

One policy solution to the problem of multiple births from IVF is that a routine pre-treatment counselling session could be available to all patients. Such a session

would give full disclosure of the treatment process. During this initial information giving session patients would have the opportunity to be educated about the SET treatment process. Prospective patients may also discuss skills with the counsellor that may be instrumental to help them to navigate the stressful clinical process. Such skills may help them make the relevant decisions that they will need to make along what could be a long course of clinical treatment. After such an initial counselling session the clinic's counselling service will then be an area of the clinical environment that every patient will be familiar with. This should mean that the counselling service becomes a place that all patients will be comfortable and confident to access at any time during their treatment. In this way the initial mandatory counselling session allows the counselling service to become naturalised or embedded within the culture of the clinic.

For the counsellor who is engaging any patient in a discussion about SET, it would be important to first address any misconceptions about the role and purpose of the patient's visit to the counselling service and also define and explain confidentiality issues. My discussions with UK infertility counsellors revealed that their patients felt that there was stigma attached to attending counselling. I was also told that patients felt that they may be judged in the counselling session and, as a result, treatment may be withheld (see chapter 7.4). It is important that the counselling service is not perceived as an assessment of fitness for treatment and that counselling is considered a neutral area of the clinic for the patient's voice to be heard. In a study by Lee and colleagues that interviewed 66 counselling staff in the UK, one counsellor commented: 'This [involvement in the welfare of the child assessment] is completely away from my counselling side... you use your counselling skills to elicit information to see what's going on, to see what's not being said, but the patient considers you to be kind of a judge in a sense and, really, to a certain extent you are, because you then determine whether or not something else comes of this matter' (Lee *et al.* 2013). To support this principle of neutrality, BICA has argued that centres should use counsellors to assess patients under "welfare of the child" requirements only when it was clear to patients that they were not undertaking such assessments in their 'counsellor' role (Blyth 2008). Counselling needs to be promoted as a simple normative experience. It should be

promoted as being an easy way that any patient may be helped during their time at any clinic. Once issues about the purpose of the visit to the counsellor are clarified, counsellors may then allow the patient to explore and determine what is it that they desire and seek and explore the wider implications of their desires. Both physical and emotional implications of the treatment process can possibly be overlooked in the excitement of the potential treatment outcome. The role of the counsellor is to allow a space for discussion and reflexivity while supporting any patient's decision with realistic information. This information should include the benefits of engagement with SET for the health of the mother and potential children born.

During the counselling session the counsellor can direct the patient on how to voice their needs and interact effectively and collaboratively with all the clinic staff. Prior to IVF treatment counselling space can offer a space where patients may get advice on how to communicate with the clinical team and state their needs. They can be directed on ways of asking for realistic treatment while being informed of the limits of the doctor and nurses ability to provide this treatment. The clinic's policy with regard to SET can be discussed in this context. The counsellor can situate discussion and information about SET within an overview of the medical process, what to expect during the treatment process and how to effectively communicate with the IVF clinic team. Any pre-treatment counselling session could take place either in an individual or group setting. A group setting allows for attendees to have an opportunity to discuss their ideas, attitudes, and concerns with others who are also about to embark on infertility treatment. Group counselling may provide psychological services to the greatest number of people for the least cost. However privacy and appointment flexibility may be lost. Flexible options could be available to each patient tailored to individual need.

If the patient has proper opportunity to explore their self identity and their relationship with infertility and its treatment then it is possible to argue that the IVF clinical process may be transformative. This is because although it a technique to circumvent infertility, the patient's engagement with the technology will foster a new

identity for the infertile self regardless of treatment outcome. Throsby endorses this very positive aspect of treatment in her description of it as “material-discursive action” (Throsby 1994:47). Throsby reflects Foucault in that she presents a study of IVF as a technology whereby she reveals new identities and norms that are produced through the negotiation of many power relationships. Franklin also trusts the transformative nature of IVF technology. She is of the opinion that a patient’s interaction with it will produce new ways of thinking about and understanding relatedness (Franklin 1999). A patient may be able to consider their motivations for engagement in the technology and their understandings of parenthood. Through counselling as a unique forum for expression, any IVF patient may begin to exert agency over their body and over the IVF process itself including decisions regarding embryo transfer practises. Through exploration of the IVF experience and the infertile woman’s interactions with it may allow a patient to let go of a known way of being and realise her relationship with infertility through new eyes.

Foucault saw the physical body, as a resource to meet the interests of the state, and therefore a proper and significant role of state is population management. This encourages the production of knowledges that allow the state to scientifically analyse the population and subsequently through such knowledge the state can therefore introduce policies, which regulate our behaviour for the good of the individual and therefore the state. Their paramount objective is to keep the population happy and healthy and therefore productive. Foucault’s theory is one that can be deemed appropriate as a backdrop to the state interest in reproductive health policy (see chapter 5). Dispute being restricted by cost, in the private sector and funding in the NHS sector, the widespread adoption of IVF has resulted in a widespread increase in multiple births. These are detrimental to the health of individuals concerned. Public health policy has sought to address this issue by setting limits on embryo transfer numbers and promoting SET within all UK clinics.

Multiple births that occur from IVF are viewed as a sociological issue for this investigation. This is because the technique shapes the form of the family unit. Increasing the number of twins and higher order multiples in society has a consequence for the stability of the family unit and then has a wider consequence for health and social care institutions. One limitation of my research into public health policy to work towards elimination of multiple gestations in IVF was political. Currently the HFEA is an established internationally revered institution that has the authority because of the Human Fertilisation and Embryology Act to put in place enforceable public health policy to govern IVF clinical practice in the UK. At the time of this research its future was in question and it was likely that it would be dismantled and its functions passed to the broader umbrella of the Care Quality Commission. There was concern that the professionalism and specialism currently proffered by the HFEA could be nurtured by the CQC. The HFEA was rerieved in January 2013.

The HFEA can still make improvements to its current policy provisions. To continue to benefit fertility patients it should interpret the legislation and formulate policy to manage IVF clinics in a way that benefits them. In the UK there is a national need for a high quality of service for medical care. The way in which this care is administered influences society as a whole and not only those who are in direct need of it. Fundamental to human life, the embryo deserves the highest regard and consideration in legislature, policy, and health care. In chapter 5, I outline research conducted in the US by Cussins, which confirms the need for a stringent and powerful policy and enforcement presence. IVF clinics in the UK like the US, very often fall into the realm of private medicine. A strong authority is required to break through, what Cussins refers to as the barriers of naturalisation and routinisation. Cussins develops these notions from the Foucauldian concept of naturalisation. Clinical practice, language, information and patient support will all become routine and naturalised according to the agenda of the private medicine without the presence of legislation and public policy. Such public policy requires a specialised apparatus for dispensation, currently satisfied by the complex functions administered by the HFEA. However the interviews that I undertook with

counsellors indicated a higher disregard for health policy pertaining to counselling provision in both private and smaller clinics. This division may be narrowed by the regulatory and surveillance powers of HFEA and its authority to navigate the agenda and administration of clinics offering private medicine.

Throsby researched IVF failure and revealed the invisibility of this failure at the IVF clinic and in discourse pertaining to the IVF procedure. Multiple embryo transfer practice is a result of the failure that is inherent in IVF as a treatment for infertility. I propose that counselling in the clinic may serve as a forum to allow women to give voice to their attitude towards and experience of this failure. The counsellor may direct and allow women to explore the particular ethical dilemma that any patient will find themselves in, between desiring children and adhering to responsible infertility treatment.

The social and historical context of reproductive choice has changed dramatically over the last fifty years. Infertility has become significantly more complex for women and infertile couples medically, socially, culturally and psychologically. The multiple births that have directly resulted from multiple embryo transfer practices are a social problem and counselling within the IVF clinic may be a meeting place to connect this broader social problem to the complicated experience of any individual engaged with infertility treatment. In this way counselling may function as a bridge to integrate personal desire and public conflict. Currently, a more clearly defined and comprehensive legislative framework, regarding the administering of counselling on an individual clinic level, could overcome the inconsistent provision of counselling in UK clinics. This framework could offer informal on-site counselling around the time of a patient's initial consultation to discuss the use of elective single embryo transfer for each individual patient in the clinic.

Counselling has not emerged as an adequate means for this yet and this is because power relationships in the clinic and economic barriers have, so far, prohibited it from being a vehicle for facilitating personal autonomy. My research

indicates that in many UK infertility clinics counselling is underutilised. In smaller clinics and private IVF clinics counsellors told me that they felt that the counselling service available to patients was perfunctory. In their clinics counselling only existed in order for the clinic to adhere to the minimal obligation of an offer of counselling to patients, which enables the clinic to gain and maintain their licence with the HFEA. This was reflected in previous research into the counselling provision of British infertility clinics (Hernon *et al.* 1995). In this research 68.4% of UK infertility counsellors described the support at their clinic as inadequate and the research concluded that overall patient uptake of counselling was low and that the counselling provision could be improved.

The counsellors that I interviewed told me that they had very little or no discussion about SET with patients. I was told that the clinician and embryologist at the clinics they worked out of raised this topic. However figures from the HFEA showed that UK infertility clinics were having difficulty meeting the 15% multiple birth target stipulated at this time (see chapter 2). I propose that there is a strong argument that counselling may be a forum to implement SET policy in all UK infertility clinics. One study has already asserted that primary prevention is the best way to reduce multiple births (Emery 2007). The research also found that discussion surrounding transfer numbers was mostly currently undertaken with the clinician and that an in-depth assessment was required to define how many embryos to transfer and what risk of multiple birth was acceptable to patients. The research concluded that psychosocial counselling would be a strong forum for discussing this topic and may operate to reinforce the partnership between couples and the assisted reproductive technology team, allowing for primary prevention and informed consent on multiple pregnancy issues. It is important to discuss patient circumstances in depth on a case-by-case basis, as they will be influenced by a myriad of factors including their time in infertility treatment. Research indicates that the longer patients are in treatment the more desirable a multiple gestation becomes (Leiblum *et al.* 1990).

For efficient and effective delivery counselling within IVF treatment there must first

be recognition of the importance of the infertility counsellor as a valuable member of the treatment team. Expanding on current regulation regarding counselling provision in every UK clinic can help to start this process. The service of counselling can then be more fully integrated into the clinic's environment and if done so, could be used to help patients to equitably incorporate SET into their treatment plans. If the counselling session takes place early in the treatment process an initial discussion of the number embryos to transfer can be talked about and each patient's unique circumstances considered in collaboration with the clinic policy regarding SET. In this way a counselling session may act as an information session to discuss the health implications of multiple embryo transfer for children born. It can also allow for a period of reflexivity to explore patient's desires and goals within the context of the course of treatment they intend to undertake given their treatment options and the resources available. The session can equip each potential patient with the information and skills that they need to navigate the treatment process ahead. It may also help them to make any future decisions that arise as a result of their participation with it, including the decision to embark upon SET. When fully educated and prepared for any potential future treatment any patient will gain a greater confidence in any decision to embark on treatment as they can be satisfied with their overall level of care and know that their psychological, as well as physical needs are being attended to by the IVF clinic.

In the UK there has been an evolution in the psychological theoretical view of infertility over the years. There is a clearer recognition of the psychosocial issues that may arise over the course of IVF treatment for any patient. Infertility counselling is a speciality that combines the fields of reproductive health psychology with reproductive medicine. Since 1988 in the UK, BICA has helped to establish specific theoretical frameworks and professional guidelines for infertility counsellors. This, in theory, allows for counsellors to identify and act upon the psychosocial issues relevant to the infertility treatment process. Counsellors are in a position to play a critical role in the management of any IVF cycle and to be an indispensable accessory to the clinical treatment process. My on-line research into patient opinion about SET gives evidence of the complexity of patient feeling surrounding SET (see chapter 8). A visit to the counsellor to discuss SET, and the



issues that pertain to it as a treatment, may serve to minimise psychosocial stress and trauma that surrounds it as a treatment option. All members of the reproductive medical team at the clinic may give information and advise and even counsel and console patients. However, it is infertility counsellors who are the mental health professionals that are trained and qualified to provide specialised levels of psychological assessment and psychotherapeutic intervention.

Studies have shown that patient dissatisfaction with infertility treatment is influenced by the total quality of care management at the IVF clinic they attend (Domar 2004). This inherently involves staff-patient communication. Common patient complaints include: insufficient time to talk about concerns and questions; insufficient information provided; poor understanding of medical advice; and lack of empathy expressed by medical staff. These findings were reflected in my research undertaken in Canadian IVF clinics both as a patient in my conversations with other patients, and as a researcher at clinic support groups (see chapter 3). These concerns were also raised in the HFEA evaluation of SET policy in the UK (see page 63). In this evaluation patients reported that information and discussion surrounding SET was lacking or absent at the clinic in which they sought treatment.

Improved patient-centred communications may be a feasible and obtainable remedy for these difficulties. This would involve a greater scope for patients to raise their own concerns at the clinic about the treatment process. Patient centred communications, which support an emotionally focused approach, have been shown to be particularly helpful in medical situations that are uncontrollable and unpredictable, such as is the case with IVF treatment (Boivin et al. 2005). Infertility counsellors can serve an important role to clinic staff by educating them on improving staff-patient communication around the often sensitive and delicate issue of undertaking SET in order to better meet the overall psychological needs of patients. The benefits of effective clinical staff-patient communication have been documented (Weinman 1997). Short-term benefits include better adherence to advice, increased patient recall, greater comprehension, more confidence in

advice, more positive appraisal of quality of service, and reduced emotional reactivity. Long-term benefits include better coping, better decision-making, improved patient self-management, quicker emotional recovery, and increased patient satisfaction. My interviews with UK infertility counsellors indicated that attitudes of the clinical team with regard to the promotion of psychological services and counselling could be improved (see page 265).

The counsellor is trained to be in a unique position to act as an interconnection between the psychosocial issues of the patient and ethical issues of the clinician while endorsing the public policy requirement that every clinic has in the UK to promote SET. In a counselling session the counselling professional will confront the ethical and legal issues pertaining to any potential treatment. In the context of discourse pertaining to SET, the counselling space may offer an opportunity for both issues to be clarified and consolidated. The counsellor is in a singular position to facilitate the decision-making process, information processing and address the psychological ramifications of decisions. They are qualified to identify the concerns of the patient within the context of their relationship with infertility as a disease and discuss these concerns and their relevance to any treatment that may be undertaken while promoting the application of ethical values.

In promoting SET for the IVF clinic, counsellors may be viewed as an interface between psychological and ethical issues. In promotion of SET there may be a conflict between the basic moral principles of patient autonomy and beneficence, nonmaleficence and justice (Beauchamp and Childress 2013). The clinician's obligation to 'do no harm' may in the promotion of SET clash with the principle of patient autonomy. The clinician may refuse to transfer multiple embryos in order to refrain from harming the patient and their potential offspring. This refusal may compromise the patient's autonomy. However, because the principles of 'do no harm' is at the core of the Hippocratic Oath it may take precedence over decision making.

Counsellors are trained to allow for the integration of medical and psychosocial

aspects of each step of the IVF process. These skills could be successfully utilised to influence any clinic's SET policy. Infertility counsellors can provide psychological assessment; insight and judgment that can assist the medical team in making decisions about patient care, including any patients' suitability for SET. Infertility counsellors are trained to be of valuable assistance to all clinic staff. If the counselling service is fully integrated into the clinic then counsellors will be in an accessible position to educate all staff in patient communication skills. This may include skills necessary to promote SET. Feedback from patients to counsellors regarding SET may be imparted to staff members so that policy pertaining to SET may be recommended in a way that takes into consideration the psychological needs of any patient.

An assumption of counselling for patients to promote any clinic's SET policy, is that when they know what to expect, regarding any prospective SET procedure or multiple embryo transfer procedure, patients will benefit as a result of an enhanced sense of control and more informed decision making. The individual patient personality and attitude to their medical condition will vary and therefore influence the way in which they process the information given. This is why the counsellor is a valuable instrument in imparting information. Their service will afford the opportunity for discussion, contemplation and reflection. This type of interactive decision making will not be present with written information giving or by face-to-face information provided by other members of the clinical team.

Any patient will be able to maximise the treatment available to them if they are: well-educated, know what to expect, and are provided with sufficient information to help them in decision making. The counsellor, with the aid of good communication and a teamwork approach with other clinic staff, are in a position to share information with each patient about SET and its impact on the treatment process. This allows any patient to make a decision with maximised informed consent and peace of mind. For the patient to make a decision to embark upon SET there should ideally be a clear discussion of their diagnosis and their suitability for SET in

relation to such diagnosis and a comprehensive and clear description of the SET treatment. Here the benefits and risks of SET may be explored as well as the benefits and risks of alternative treatments, including no treatment. The counsellor can give information on the higher health risks involved with a multifetal pregnancy, and clarify the SET treatment policy of the clinic and the patient's suitability for using SET. This can help to eliminate false hopes about SET and also assist in calculating its financial viability for each patient. This allows each patient the opportunity to minimise the possibility of future regrets and distress when embarking upon the treatment process.

When delivering guidelines for clinics regarding the staged adoption of SET over a period of years, the HFEA made decisions regarding infertility treatment on the patient's behalf. My research into patient opinion (chapter 8) displays considerable resistance to this decision. Therefore to implement this policy equitably the emotional mindset of the patients themselves should be considered and if necessary adequate support should be offered and provided for these decisions on a patient level. This could also be coupled with financial incentives such as free frozen follow up cycle support. In future, we need to empower IVF patients, by ensuring that they have all the necessary information to be able to make fully informed decisions that are consistent with their own goals and values. Robust regulatory apparatus is essential in any implementation of the incorporation of new systems into the clinic environment.

## **APPENDICES**

- 1) An example- information for patients at IVF clinic in Toronto where I was a patient -2006**
- 2) Elective single embryo transfers during 2009- year one HFEA policy evaluation**
- 3) Multiple pregnancy rate in 2009- year one HFEA policy evaluation**
- 4) Certificate of ethical approval for research**
- 5) An example of an interviewee participation consent form**
- 6) Interview questions for IVF counsellors in the UK**
- 7) Chart detailing global embryo transfer techniques**
- 8) Chart detailing embryo transfer numbers in European countries in 1999**
- 9) Chart detailing embryo transfer numbers in European countries in 2005**
- 10) Chart detailing embryo transfer numbers in European countries in 2009**
- 11) Interviews with two IVF clinicians in Toronto, Canada**
- 12) Details of IVF support group meeting in Toronto, Canada**

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