

**Donor Insemination – an exploration of the
psychological issues for couples who undergo
treatment and those who have a DI child.**

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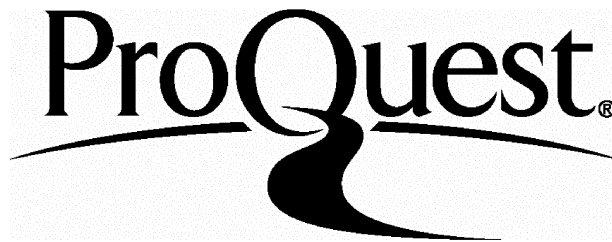
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ABSTRACT

This descriptive study examines the psychological effects on men and women of fertility treatment by donor insemination. Issues considered are: telling the child, levels of distress and adjustment and views on counselling and information needs. Participants were drawn from two settings, a local hospital clinic and the support group, DI Network, and totalled 43 men and women in treatment and 83 who were successful in having a DI child. Measures used were the HADS, the more recent Fertility Adjustment Scale (FAS) and a questionnaire designed specifically for this study.

For those in treatment the study found relatively high levels of distress and anxiety, and results on the FAS suggest men and women experience difficulties adjusting to their fertility problems. The concerns of couples in treatment were preoccupied with becoming pregnant and donor issues. For those couples who have a child main concerns were about telling the child and the child's right to information about the donor. Gender differences were also found. There were few requests for counselling and couples reported getting little information on the emotional impact of DI or how to tell your child. Distress levels were significantly higher in the group who was uncertain about telling their child and findings indicate that the educational level of couples is a possible factor in deciding to tell the child about his/her origins. The effects of secrecy and stigma in DI are also considered. Accounts from couples who have told their child indicate that it can be a difficult process, and more research is clearly needed in this area. The implications of these findings are discussed in the light of current literature and service needs.

CHAPTER ONE

INTRODUCTION

“I recall the busy subfertility clinic on Monday afternoons. The long narrow corridor was lined with several chairs occupied by couples waiting to see the doctors. They sat silently with anxious and concerned faces” (Djahanbakhch, in Emmy Jennings, 1995, p.218)

Couples who discover they have fertility difficulties are faced with difficult and perhaps emotionally painful decisions. One treatment option for couples is donor insemination (DI). The use of fertility treatments has often aroused heated debate, and DI is no exception. In a recent television news debate there were accusations that the child was a “commodity, not a product of the parents love” (Widdicombe, 1998) and that DI, in particular for single women represents the “moral decay of society” (Campion, 1998).

This piece of research examines the emotional impact of DI on couples. This study explores the differences between men and women who are currently in treatment and those who have had one or more child through DI. Issues about secrecy, the treatment itself and levels of distress are addressed. A secondary aim of the study was to use a newly developed Fertility Adjustment Scale (FAS, Glover et al. in press) with a sample of men and women undergoing donor insemination treatment.

This chapter introduces the subject of DI and discusses its position in the wider historical, social and ethical context of this treatment. The psychological implications of DI for men and women are then discussed. Literature is also

reviewed regarding current knowledge on telling a child born as a result of DI about his/her origins.

1.1 Infertility and donor insemination

The definition of infertility is the "inability of a couple to conceive after one year of intercourse without the use of contraception" (Mosher & Pratt, 1982, p428). It is estimated that 10% of couples are affected, with approximately one in six seeking professional help (Mosher & Pratt, 1982).

The impact of an infertility diagnosis and the change in life plans and expectations of the couple in addition to the decision to undertake any treatment obviously takes its psychological toll. Whilst more recent reproductive technologies offer new hope, infertility may mean an extended period of treatment for the couple, sometimes over many years. Investigations and treatments are often lengthy, intrusive, time-consuming and expensive, both financially and emotionally. Little is known about the impact of fertility treatments on those who undertake treatment, and in particular, DI which has had a colourful and controversial history.

Whilst infertility is usually seen as something that mainly affects women, male fertility is relatively common, accounting for 40% of infertility in couples. Donor insemination is a method used when the male partner has fertility difficulties, which could be any of the following: azoospermia, which means that there is no sperm present, usually arising as a consequence of the absence of testicular function; When there are some sperm present (subfertility), but in low numbers or low motility, the causes are many and various; it may be that the male partner has a

genetic disorder such as Klinefelters Syndrome which accounts for 1-2% of male infertility; some men may have congenital absence of part of the system of tubes and ducts that fail to develop. Other reasons that DI is used are unrelated to infertility for example, the man has an inherited disease that they do not wish to pass on to their child or had a vasectomy in the past, with a failed reversal operation. In all the above cases the couple is faced with the decision of using donated sperm.

Recent research suggests that the experience of male subfertility is characterised by uncertainty (Glover, Gannon, Sherr & Abel 1995). As a result of this uncertainty there may be different psychological implications for these men, compared to those who receive a definite diagnosis such as 'no sperm present'.

Today the world of reproductive technologies becomes ever more complex and advanced. New treatments for male infertility, such as MESA (Microepididymal sperm aspiration) and ICSI (Intracytoplasmic sperm injection) may offer new hope for men who are either azospermic or who have poor sperm count or motility.

For the purpose of this research I shall be using the term 'fertility difficulties' and 'infertility' to encompass all reasons for seeking DI.

'Genetic death' is a term that has sometimes been used to describe the experience of infertile men who know they can never have any blood descendants. For men who undergo DI treatment, the treatment does not 'take away' the diagnosis of infertility, but merely finds a way to deal with the problem. As a result the man may feel forgotten in the treatment, as his partner becomes the focus of all treatment. As stated in the 'British Infertility Counselling Association' practice guide:

"DI does not do away with a man's condition of infertility but only deals with his childlessness by giving him the opportunity to nurture a child conceived by his partner" (Snowden & Snowden, 1997, p10)

In terms of the procedure of DI, the sperm from the donor has been screened for diseases such as HIV, hepatitis and sexually transmitted diseases. Sperm is then frozen and quarantined for six months before use. Clinics match the donor sperm on some physical characteristics as the male partner, for example, skin colour, hair and eye colour, body build and blood group. The identity of the donor is kept strictly confidential although some clinics release non-identifying information such as profession and interests.

The Human Fertilisation and Embryology Authority (HFEA) currently hold a register of all donors, recipients and treatment cycles. The purpose of this register is to enable people over the age of 18 to find out if they were born as a result of licensed fertility treatment, and if so whether they are related to someone they wish to marry. There may be provisions in the future for children born as a result of these treatments to obtain further information on donors.

The DI treatment is performed during the women's fertile period each month. Blood and urine hormone tests and ultrasound scans ensure that the timing is precise. Drugs are sometimes used to stimulate ovulation and as a result can increase the risk of multiple pregnancy and births.

The HFEA (1995) reports that in 1995, 6,250 women were treated with DI receiving 17,857 treatment cycles. These resulted in 1,557 births, which represents a live birth rate per cycle of 8.7%. However, chances of success do decrease with the age of the woman.

Before DI treatments begin it is likely a couple may have already attempted other treatments. These can include ovulation induction, insemination using the partners sperm or in-vitro fertilisation (the fertilisation of the woman's egg with the man's sperm and then placed in the uterus transcervically - IVF).

The process of receiving a clear diagnosis may also have taken many months and this may be prior to making the decision to attempt DI. A geographically accessible clinic has to be found, fees and NHS funding investigated and waiting lists enquired about.

DI is technically a simple and painless procedure. Semen from a fertile male donor is placed in the reproductive tract of the woman, using a narrow plastic tube; it is carried out at the fertile time in the woman's cycle, when an egg has been released from her ovaries.

However, despite the relatively simple physical procedure there are often complex psychological and emotional reactions. At the beginning of treatment the couple may be feeling hopeful, anticipating success, and waiting anxiously after the insemination. If the treatment is unsuccessful and menstruation occurs, feelings of disappointment, frustration and despair may set in. This disparity between the technicality and the emotional experience of the treatment is something I hope to explore in this piece of research.

Pfeffer (1993) points to how childlessness is often interpreted as a voluntary, reversible condition, which is both desired and self imposed, though often the woman who chooses not to have children is deemed as 'selfish' or as a 'career' woman.

DI throws up many religious and moral debates and continues to arouse public interest and scandal, as do other fertility treatments. Modern culture abounds with images of fertility and motherhood and images of 'potent' man and 'fertile' women. (An example of this is in the fashion world with a dress collection based on images of conception to birth: The Times Magazine, 1997)

In many cases both information and treatment for infertility become focused on the woman, for example many units are located within obstetric and gynaecology departments. The focus centres upon the woman achieving a pregnancy. Yet what becomes of the couples needs as they embark on this treatment? How much information can they access about their infertility difficulties and what support is available for them in attempting to come to terms with this? Another major issue is in consideration of the welfare of the resulting child from these reproductive technologies and how the family relates to them; is the method of conception spoken about or not?

This also raises the issue of how the child is registered at birth. Until 1990 when the HFEA Act was passed there was no way of registering the birth of a DI baby. This legal loophole resulted in couples registering the male partner as the child's father. Now a woman's husband/partner is deemed to be the legal father of a child born as a result of treatment. The semen donor has no legal rights or responsibilities concerning any child born as a result of his donation.

1.2 The historical context of DI

Donor insemination is one of the oldest assisted reproduction techniques and continues in many ways to be shrouded in secrecy. In order to examine its place in contemporary society it is necessary to look briefly at the political and historical context of fertility issues and earlier developments in treatment. Scutt (1990) provides an interesting perspective on childbearing and sexual reproductive choices in the early centuries. Between the mid 1870's and the 1930's the birth rate in Britain fell, causing great alarm amongst politicians and moral figures of the time (Pfeffer, 1993). This was viewed as a threat to both national and imperial security. There was at this time a popular belief that the epidemic of male sterility was caused by degeneration and the "development of the intellect at the expense of the body" (Pfeffer, 1993).

According to Downie (1988) most objections to DI come from religious and legal fields. Ethical arguments have centred on the status of DI children, whether they should be informed of their genetic origins and donor anonymity. Catholicism, Judaism and Islam have religious objections to DI on the grounds that it involves the sin of masturbation and that DI equates with adultery. Mary Warnock who chaired the Warnock Committee on the Human Fertilisation and Embryology stated in response to this argument that "there is no analogy whatsoever between adultery and DI. The motives for DI are procreation and the motives for adultery are pleasure" (Downie, 1988, p95)

Other religious concerns centre on the possibility of incestuous marriage, as the donor remains anonymous. As recently as 1987 the Vatican documents opposed DI

with the argument that the conception of a child must be a result of his parents love rather than as a result of medical or biological techniques.

In the late 1930s DI was provided as a way of overcoming involuntary childlessness, but remained still shrouded in secrecy with the predominant focus on the woman. In the early days of DI doctors mixed donor sperm with that of the husband, thus introducing an element of uncertainty. This was seen as a source of great psychological help to the husband when raising the child.

In the interwar period the Eugenics society took up a stance against DI believing it to be an example of a scientific system whereby a genetically superior race was created. Certainly at this time the criteria for selection of donors suggested a belief in the inheritance of intelligence and personality. This eugenic argument was perhaps influenced by political events of the time and the awareness that the Nazis had attempted to fulfil some of these fantasies. (Pfeffer, 1993).

In the 1940s insemination techniques were widely used in farming and medicine in an attempt to increase the output of food. Moral panic seems to have surrounded DI at this time. It was seen as immoral, and illegal, reducing humans to the status of cattle. All involved were criticised; the doctors as ethically rootless, the donors as 'stallions' and depraved men, the wives of the donor and the female recipient all coming under attack. At this time only the infertile man was spared, deemed perhaps as 'beyond contempt' (Pfeffer, 1993)

There were calls at this time that DI should be outlawed and formal legislation brought against its practice. This did not happen, mainly due to fears that it would

simply continue underground. Margaret Jackson was a pioneer of DI at this time and with her influence, consent forms for husband and wife were available by 1944.

Once included as part of the NHS services (in 1973) clinicians seemed uncertain how to incorporate DI and male infertility into their everyday practice and services for the infertile were often relegated to the outer fringes of the NHS. (Pfeffer, 1993)

Demand for DI grew and by the 1970s it was clear that many couples had heard of this procedure as a way of solving their fertility difficulties. The birth of the first test tube baby (IVF) in 1978 illustrated the need for regulation of fertility treatments and the Warnock Committee report was commissioned. Social and legal arguments were discussed in the Warnock report (1992-1994). There were concerns that as a result of the introduction of a third party (donor sperm) in DI the couple's relationship would be threatened or that the man may experience feelings of inadequacy. Other anxieties were that the wife might feel emotionally closer to the child and that the child may feel different from its peers. However, there is no available evidence to suggest DI leads to higher levels of marital breakdown. In contrast, there is even some evidence that the relationships of those couples who have gone through DI treatment are generally more supportive and stable. (Snowden & Snowden, 1994)

The Warnock report made recommendations for those treatments that included egg or semen donation and called for the establishment of an external body to regulate research and treatments. The Human Fertilisation and Embryology Act of 1990 followed this and considered all legal, social and ethical implications in order to protect the public. The Human Fertilisation and Embryology Authority was then set

up, providing today, advice for couples and a code of practice to ensure the appropriate provision of services.

The need for counselling was also recognised in the HFEA act of 1990. This act stated that it was a legal requirement that couples considering DI must be given an opportunity to receive counselling about the implications of the steps they were taking, before consent is given for treatment to go ahead. According to HFEA definitions there are three broad types of counselling which are outlined below:

Implications counselling – this considers the implications of the outcome of the treatment on others, including those directly concerned, e.g. the child and parents. It also considers the DI in relationship to others such as any other children or wider family and friends.

Support counselling – this aims to give support at particular times of stress during treatment.

Therapeutic counselling – this counselling focuses on the resolution of underlying psychological problems related to the presence of fertility difficulties.

It may be rather misleading that implications counselling has the title of 'counselling' as is something routinely built into the couples' treatments and can at times become somewhat 'prescriptive'.

There is an obvious tension between the need for counselling and the role of assessment, as couples receive their implications counselling prior to treatment. The law requires that when assessing the treatment needs of couples, account must be taken of the welfare of any child who may be born or who may be affected as a result of the treatment (HF&E Act, 1990, Schedule 13 (5)).

The dilemma for the counsellor is in being able to create both an environment where the couple can be open about their anxieties and fears and also in being able to make a judgement about suitability for treatment. Thus the couple may be wary about voicing their uncertainties and true feelings due to the fear that they will then be excluded from treatment. The counselling function of these sessions may be further hindered when carried out by the doctor.

In many ways it can be argued that DI is treatment for a social rather than a medical problem. Downie (1988) points out an alternative to DI would be for the woman to conceive naturally with another man, but since this is socially unacceptable DI is used to solve a social problem. This relates to further implications of these types of treatments where as infertility is not cured and ever more complicated treatments are developed, there exists perhaps a pressure for the couple to keep on trying. This is what Rothman (In Scutt, 1990) calls the 'burden of not trying hard enough'. For example, how many months or years of temperature-taking, regulated sex and repeated failed cycles does it take before giving up? It could be said as Scutt (1990) points out that if there are other choices then the "social role of infertility will always be seen in some sense as chosen; they chose to give up" (Scutt, 1990, p140)

1.3 Psychological implications of DI

A diagnosis of infertility for a couple often comes as a shock and with the slow realisation that they cannot give each other a child biologically (Clamar, 1980). It also challenges the cultural designation of roles where the man is the 'procreator' and the woman the 'birther'. In this sense infertility is; "A life crisis usually dealt with in

a psychosocial vacuum, often accompanied by identity crises and guilt on behalf of the infertile partner" (Clamar, 1980, p173)

Raphael-Leff (1991) provides a useful psychoanalytic viewpoint on the psychological impact of a diagnosis of infertility. The period of treatment is seen as a particular stressor for the couple, and further anxieties are raised when the treatment period is relatively undefined with few boundaries to determine an end point. At diagnosis the individual may feel bereft of their hopes and plans, disillusioned in their body's natural functioning.

Infertility is seen to affect various domains of the couple's lives, their work, managing clinic appointments and causing tensions between the couple. In DI treatment most couples are allowed a certain number of treatment cycles, in the NHS in the UK, 12 usually being the maximum. However, along this path the woman may have had to undergo various other investigations or combinations of treatment. These cycles can be taken over many years, which can be anxiety provoking in itself as age becomes an added factor. It is perhaps the persistent and unsuccessful treatment of infertility that feels the most wearisome and damaging, instilling deep-seated pessimism.

Raphael-Leff (1986, in Raphael-Leff, 1992) suggests that in treatments such as DI, sexuality and procreation for the couple can become further separated by fantasies that may arise regarding the identity of the father, now perhaps seen as the intervening doctor. It is these emotional conflicts and unconscious fantasies that

continue to operate in treatment and contribute to adjustment and resolution of this crisis. Thus strategies of adjustment and coping with the vicissitudes of treatments depend on working through the emotional reactions to the condition and to the professionals involved.

Literature on infertility in the 1970s frequently referred to the 'emotional rollercoaster' of infertility, describing the euphoria of the possibility of pregnancy and the despondency when it fails. Time is a major factor here, and the way in which the couples' emotions may revolve around the woman's menstrual cycle.

Raphael-Leff (1986, in Raphael-Leff, 1992) also points to a variety of psychological disturbances that she sees as linked to the state of infertility. These include symptoms such as depression, low self-esteem, guilt, psychosomatic and anxiety reactions, magical thinking and compulsive rituals. Whilst she acknowledges that the reaction to infertility is highly individual she draws out common themes. One of these themes is about the way in which the couple may develop a heightened emotional attachment to the "god like" baby maker infertility expert who has magical powers attributed to him/her. She states that the uncertainty with which the couples face in their future, a sense of lack of control and biological dependency, all lead to the development of this state. Indeed, in entering a fertility treatment unit the many photos of babies that surround one, placed even beside the examining couch, are striking.

Research into the area of infertility had previously involved a search for aetiological factors where emotional factors are presumed to be causal. Theorists here propose a 'psychosomatic' argument where causal factors have often been assumed to reside

with the woman. Research in this area is scarce and difficult to validate. In addition these models carry few implications for understanding how couples adjust to infertility.

Demyttenaere et al (1988) examined whether there was a relationship between anxiety levels and conception rates and concluded that there was a significant relationship. However, a criticism is that the model is 'woman blaming', and although stress plays a part in how the couple view and deal with their fertility difficulty and day to day life, there is a theoretical leap to attribute causal direction. Nevertheless, there is no doubt a need for an integrated bio-psychosocial approach to the new reproductive technologies, which addresses psychological factors through both diagnosis and treatment (Stauber, 1986).

Another way of conceptualising infertility is as a crisis. Here, the heightened emotional distress experienced by couples is seen as a consequence of infertility rather than the cause. Berger (1980) and Menning (1977) promoted this standpoint viewing infertility as a major life crisis where it is "a currently unlovable problem that threatens important life goals, taxes personal resources and arouses unresolved major problems from the past." (Stanton & Dunkel-Scheller, 1991, p102). This is similar to the grief model, whereby for 'healthy' adjustment to the state of being infertile one must first work through ones feelings and mourn often numerous losses. In terms of DI the ability for the couple to grieve for the loss of their own 'biological' child is essential and time for the adjustment to the realisation of this loss is necessary. Couples may indeed vary in how they resolve this difficulty, for some it may be accomplished relatively easily, whilst for others it may require a longer

period of grieving. However, critics argue that this theory views infertile couples as similar, promoting a 'homogeneity myth' (Kiesler 1966, in Stanton & Dunkel-Scheller 1991). Thus individual variation is minimised and factors that may help or hinder couple are given little attention.

An alternative view is of infertility as a "stressful experience" thus allowing greater variation in the individual response to their situation. Lazarus & Folkman (1984, in Stanton & Dunkel-Scheller, 1991) indicate 3 major domains that are indicators of successful or unsuccessful adjustment to infertility. These are morale and sense of self, social functioning and somatic health. Their definition of stress is as follows: "a relationship between person and environment that is appraised by the person as taxing or exceeding his/her resources and endangering his or her well-being" (p19) Moos & Schaefer (1986) went further to define 5 adaptive tasks which follow:

- 1) The meaning and personal significance of the situation
- 2) Confronting reality; respond to requirements of situation
- 3) Sustaining relationships (social functioning)
- 4) Maintaining reasonable emotional balance (morale)
- 5) Satisfaction with self image and sense of competence (morale)

Indeed, the assessment of well being and distress to signify adjustment is well established in literature on adjustment to stressful experiences and is certainly useful in considering the experiences of those on DI. While concepts such as 'reasonable emotional balance' may be difficult to quantify, it is suggested that levels of distress that approach clinical significance result in the lowering of self worth and role functioning.

It is therefore important to consider the variation in individual response to receiving a diagnosis of infertility and considering DI as an option (Stanton, 1991). As suggested by the guidelines provided by BICA, alternative courses of action should be considered before pursuing DI. This might include consideration of a childfree lifestyle, or parenting through fostering or adoption.

In research into couples' reactions to both male infertility and DI, it was found that 6 out of 10 couples delayed several months before deciding to proceed with DI. This delay was associated with better adjustment to infertility, as opposed to perhaps being 'rushed into DI' by their doctor (Berger, 1980). This theory that delay is associated with better adjustment supports the views of Gerstel (1963, in Berger, 1980) where the inability of the couple to mourn the infertility before turning to DI contributed to later difficulties, particularly regarding unresolved feelings and hiding the man's infertility.

Certainly the literature on stress and coping contributes to the understanding of adjustment to infertility as it both specifies the conditions under which infertility is likely to be perceived as stressful and also points to the factors that are likely to facilitate or impede adjustment.

For those couples who are told of a fertility difficulty and undergo DI treatment, psychological adjustment to this news is very important. The diagnosis may be experienced as a major threat to their identity, life plans and psychological well being. Stanton et al (1992) examined coping and adjustment to infertility, looking at the differences in strategies between men and women. They found that when

avoidance was used as a coping strategy it was associated with higher levels of distress for both men and women. Men were more likely to cope through distancing, and self-control, whilst women attempted to cope through mobilising support.

Recently, a Fertility Adjustment Scale (FAS) has been developed and piloted (Glover, Hunter & Richards in press). It has been found to be a reliable measure, correlating significantly with measures of mood and distress. The measure assesses adjustment to infertility and assesses the cognitive, emotional and behavioural reactions to fertility problems. For the reasons discussed above it is probably unrealistic to expect a clear or definitive cut off point for this scale, but rather it provides a guide to how well or poorly adjusted patients are to the possibilities of childlessness.

Obviously this scale is still in the early days of development, but has identified a clinical need in this area. It is useful in that it acknowledges some of the difficulties men and women may be grappling with throughout treatment.

1.4 Gender in relation to infertility

For couples undergoing DI there is some evidence that many experience sexual dysfunction during investigation and treatment (Menning, 1977). Berger (1980) also found that men who had received a diagnosis of infertility often experienced a temporary period of impotence. (Berger, 1980, in BICA practice guide, 1997).

First hand accounts from men and women undergoing DI treatment suggest that they may have different concerns and anxieties. For example, the man may be anxious about the use of another man's semen to inseminate his partner, or be wary about his

ability to be able to accept a child born as a result of DI. He may also have many complex feelings about his fertility difficulties (Snowden & Snowden, In BICA guide, 1997).

For women the issues may be different. Although in many cases the woman has no fertility difficulties, she shares in her partner's childlessness. She may feel resentful or angry towards her male partner. There is also some evidence to suggest that women feel the need to protect their partner from any outside awareness of his infertility, thus taking the 'blame' for the childlessness. In terms of the insemination there may be anxieties around being inseminated with the semen of a man other than her partner and fears about his ability to accept the baby. Monach (1993) found that women, even though healthy and often with no fertility difficulties carry much of the burden of investigations and treatments.

Beureparire et al (1994) evaluated gender differences for those having IVF treatment and their psychosocial adjustment to infertility. They found that 30% of men and women experienced clinically elevated anxiety levels regardless of stage of treatment. Those women having repeated cycles ran the risk of developing clinically significant depressive symptoms. Following this research they called for interventions which would reduce anxiety and depressive symptomatology and which could be implemented at various times in treatment for both men and women. There may be similar concerns for men and women who undergo many treatment cycles of DI, experiencing stresses at particular points.

Blaser (1988) examined the emotional state of men whose partners were undergoing DI treatment and concluded that DI was not a threat to them and that infertile men

were not seen as a psychological risk group. Conversely, Cook et al (1989) assessed couples undergoing DI and IVF and found that men and women suffered from high levels of anxiety, but not depression. Those who suffered from high levels of distress were more likely to engage in avoidance-coping strategies. Humphrey and Humphrey (1987) suggested from their research that the man in particular needs emotional support from his wife in adjusting to his infertility and that this should be carefully considered and worked with before embarking on DI treatment.

As most services are focused on women and enabling the woman to become pregnant there is also a possibility that men become marginalised. DI and the availability of sperm donation carries with it the threat of mens' dispensability. Carmeli and Birenbaum-Carmeli (1994) found that many men did not attend the first appointment at an infertility clinic with their partner. Women are generally seen as being more accustomed to seeing doctors, more prone to fertility-related hazards and more eager to have children (Stanway, in Carmeli, 1994). They point to medical literature where the woman is consistently referred to as the patient whilst the man is merely the 'partner'. Their study examined two clinics (one in Israel and one in Canada) and the differences in how men and women were involved in the treatment. They found that in many cases the man was only occasionally required to attend the clinic and experienced additional financial burden if his wife gave up work whilst in treatment. An interesting psychological aspect of this study was when men were allowed to be present at the insemination or not. On one occasion one male partner was advised not to be present as the doctor explained he wished to protect him from the "predicament associated with seeing his wife being impregnated by another man (himself)" (Carmeli & Birenbaum-Carmeli, 1994).

They found that for many men it was also a source of extreme discomfort to be excluded from the treatment and Lasker and Borg (1987) point to the positive effect on both partners when there is greater male involvement in the treatment.

Men also referred to the production of a sperm sample as a source of embarrassment and distress, Carmeli and Birenbaum-Carmeli (1994) suggest that even the term 'sample' serves to undermine the male's contribution.

There certainly seems to be evidence that suggests that there is also a significant psychological impact on men when dealing with their infertility and undergoing DI treatment with their partner. Keedem et al (1990) found that infertile men demonstrated lower self-esteem, higher anxiety and more somatic symptoms than fertile men did. Another interesting issue is the impact of male infertility on the relationship between the man and his partner, where perhaps the man blames himself for denying his partner the right to have children.

Mahlstedt and Greenfeld (1989) suggest that the man's contribution to the reproductive process may feel as if it has been replaced by another man (the donor) in DI. However, with medical advances and egg donation treatments, perhaps the two are comparable? However, Carmeli and Birenbaum-Carmieli's (1994) research suggests that women do not view egg donation as a threat to their role, as they are required to carry through the pregnancy. On the other hand, sperm is often abundant and accessible, donation is simple and volunteers may be numerous. It is perhaps in these cases that men may feel somewhat marginalised.

1.5 Secrecy

The advance of new reproductive technologies has always tended to raise heated debate and controversy, as demonstrated by Dunn, Ryan and O'Brien (1988) who examined undergraduates' attitudes to methods for dealing with infertility. Adoption was viewed as most acceptable, with DI and surrogate mothers as the least. Whilst it is uncertain how much of an attitudinal shift has occurred in ten years, there are still frequent media reports of DI and fertility treatments and it is perhaps little wonder that couples embarking on DI treatment sometimes experience it as shrouded in secrecy.

In recent years, moves in Australia and New Zealand have been towards more open practices (Singer & Wells, 1984, Purdie et al, 1992, Daniels, 1993). However, there is still considerable evidence that many doctors advise couples not to mention the child's origins or indeed to the child if treatment is successful (Andrews 1984). This is obviously an emotive issue for couples embarking on often lengthy and distressing treatment.

As illustrated by the various religious, political and social factors described above, DI has often been controversial. Although there are more calls for openness in the area, many still involved support the principal of secrecy. Arguments suggest that it is in order to protect the child from stigma and emotional trauma. Secrecy was also seen as functional in protecting the husband, the donor's anonymity and the medical professionals (Daniels, 1993).

Recent documents on DI support the need for greater openness and advise that the couple consider telling the child (HFEA 1995; Warnock Report 1984). However, whilst the anonymity of the donor is still protected by law and there are strict

procedures so that the family cannot have access to the donor's identity, it is a difficult decision for the family to make. There may be many reasons why couples fear telling others or a child about the DI treatment. Couples may fear the reactions of those they tell, the man may feel it also exposes them and their infertility, thus stigmatising them. As regards the child there is also perhaps a fear that telling the child might damage the relationship, or put their emotional stability at risk.

With different opinions on this issue and little research into the effects of telling one's child, it is not surprising that couples are often faced with conflicting and confusing messages regarding the dilemma of openness (Blyth, 1991).

Sanschagrín et al (1993) examined the degree of openness amongst paediatricians in Quebec regarding their knowledge of DI. They found that most favoured telling the child and felt the child had a right to know. Their opinions reflect the growing trend towards openness in DI.

Research into openness in adoption is useful when thinking about couples undergoing DI. Siegal (1993) noted that for couples the issue of openness was eclipsed by the enormity of finding a baby to adopt, interacting with the professional staff and coping with their infertility. This raises the question that openness perhaps becomes an issue for couples once they have achieved a pregnancy with DI and have had the child, as during treatment they may be more preoccupied with dealing with clinic staff, adjusting to their fertility difficulties and ultimately getting pregnant.

Whilst it is clear that more doctors are changing their practices in the direction of openness, many doctors still advise couples not to tell anyone about DI or do not

address this issue explicitly. Research into whether a couple tell their child or not suggests that most parents or parents-to-be have no intention of telling the child about the nature of his/her conception. (Snowden & Snowden, 1984, Rowland, 1985, Daniels, 1988).

Daniels (1993) points out that no other forms of assisted reproduction are shrouded in as much secrecy. As donors are matched as closely as possible with the male partner, the husband is automatically the legal father of the child and the birth certificate carries no identifying mark. He suggest that this is because DI is used predominantly for male subfertility. As suggested earlier, fertility and men in the Western culture has long been synonymous with virility and sexuality. Indeed there are examples in our culture and language supporting this: to prove oneself a 'man' and stigma attached to the terms 'jaffa' and 'seedless'.

In 1989 Lasker and Borg (cited in Daniels, 1993) found that men were more likely to want to keep their DI treatment a secret and that women were more likely to cover up their husbands infertility and "take the blame". This does indeed add weight to their argument that DI secrecy is bound up with protection of the infertile male. This research also addresses anxieties about the relationship between the father and child and the concern that couples have that their child might reject their father if told about the DI.

Berger (1980) focused on male infertility and couples reactions to DI, interviewing 16 couples. He believes that the total secrecy in DI inhibits the working through of conflicts about infertility and DI. Seven out of 10 couples interviewed believed secrecy would benefit the child, as the child would not 'feel different'. Adjustment to

infertility is seen as two problem-solving stages, coming to terms with the male infertility and confronting the problem of DI. Thus the secrecy embedded in DI treatment interferes with successful progression through these two stages, blurring the two separate tasks.

1.6 The DI child

For those affected by DI, whether as couples, clinicians, donors and any resulting children there remain pressing issues around secrecy. There is very little research into the children born as a result of DI. Secrecy is still seen as important in DI programmes due to the argument that it provides protection for all 3 parties (donor, couple and child). Rowland (1985) states that the comparisons made between openness in adoption and DI are not useful, as they are very different experiences and present different problems.

Clamar (1984) revealed the gap in research here where mental health practitioners tend to only see those children who had learned of the DI inadvertently, often in dramatic circumstances. In these cases as one might expect the effect was often devastating, no matter what the age of the child.

Whilst there is currently a trend in child welfare to encourage openness in adoptions, the need for clear and helpful guidelines for those in the DI field are also called for. Daniels (1993) draws attention to the difficulty faced by couples who do wish to tell their child and lack the scripts with which to do so. Faced with the task and knowing the best age to start is therefore a daunting task. In Britain a support group now exists for people who have had or are having DI. The DI Network, which was set up

by parents of DI children in 1993, provides support for couples who are considering, planning or have already told their child of their origins. Two DI members have now written a book in conjunction with the Infertility Research Trust (My Story 1991) that parents can use in telling their child. However, little is known about the effects on the children or of the experience of those who choose to tell.

Daniels (1993) has been very pro-active in this area, calling for an increased focus on the child itself, shedding light on this previously neglected area:

"The whole issue of keeping the child in ignorance of his or her true origins and of setting up procedures to ensure that such ignorance is maintained needs to be examined very carefully"
(Daniels, 1993, p79).

Rowland confirms this by stating that it is the potential child who receives the least attention throughout DI treatment with a tendency to infantilise and not to see him/her as a child who will become an adult. Mary Warnock also supported this position in the Warnock report (1984).

Wrobel et al (1996) examined the factors that exist in the openness arrangement for adoption. They considered the level of information the children had about their birthparents, what information the adoptive parents had withheld from their child and the general level of openness reported by the adoptive parents. Overall, there was no evidence that providing information about a child's birth parents will confuse the child or lower their self-esteem. Additional evidence to support openness in the family was provided by Grotevant et al (1994) where parents in open adoptions demonstrated more empathy towards the birthparents, a stronger sense of

permanency in relationship to their child and less fear that the birth parent might try to reclaim their child.

McWhinnie (1986) argues that DI children should have the same rights as adopted children with regard to access to their birth records. Grotevant (1997) considered the development of identity in adopted adolescents arguing that a coherence of identity narratives can serve a useful purpose for adolescent development. Variation in the openness of the adoption was found to moderate the relation between family processes and the outcome for the adolescent. This may be the case for DI regarding the decision to tell the child or not. Whilst it may be relatively tempting not to tell the younger child about their origins, what are the dilemmas faced by families when their DI child reaches adolescence and questions about their identity become more pressing?

1.7 Aims and rationale of the present study

Although new reproductive technologies continue to move forward in the pursuit of ever increasing ways of helping infertile men and women to have a baby, there is still a real need to explore the psychological and emotional well-being of those who do so. Just as Sokoloff (1987) stated 11 years ago, issues regarding information on the donor, counselling for parents, the burden of the family secret of DI and ultimately the well being of the child have not been adequately addressed.

This study explores the concerns of men and women who are undergoing donor insemination treatment. It also samples a number of men and women who have completed their families through the use of DI and explores their experiences, both

past and present, in relation to fertility difficulties and the child/ren they now have. Thus two different phases in the field of donor insemination will be examined: in treatment, and the future after successful treatment. Data is collected from two different settings with the use of postal questionnaires.

The issues surrounding making the decision to tell the child or not is still in its infancy. However, this research aims to provide some insight into those families who plan to tell, or indeed have done so. The role of counselling and implications counselling is also explored with a view to providing recommendations for furthering psychological support for couples undergoing donor insemination treatment.

The following research questions will be addressed:

Treatment Group

1. What are the concerns of men and women undergoing donor insemination treatment?
2. How do men and women differ in terms of distress, mood and adjustment when in treatment?
3. What are the counselling and information needs of couples in treatment?
4. What are the experiences for this group when telling others about DI and in making the decision of whether to tell their child his/her genetic origins?

Group with a DI child, and no longer in treatment

1. For those men and women who now have a child, what are current levels of distress and mood?
2. What are the concerns for men and women regarding donor insemination once they have had a child/ren?
3. Looking back on treatment, what are the couples' counselling and information needs?
4. Is there any relationship between proximity to DI treatment and levels of distress and effect on mood?
5. What are the main concerns for men and women about telling their child/ren and what has been their experience of telling?

CHAPTER TWO

METHOD

2.1 Overview

This descriptive study surveyed 59 men and 67 women who were either currently in or had completed their donor insemination (DI) treatment. It examines the current concerns and expectations of those undergoing treatment and those who have completed their families through this method of fertility treatment. Men and women were recruited from a teaching hospital clinic and from the support group 'DI Network' (which emphasises the importance of telling children about the nature of their conception). Mood (HADS) and adjustment to infertility (Fertility Adjustment Scale; FAS) were assessed.

2.2 Setting

This research was carried out in two settings which are described separately below

Hospital clinic sample

Participants were recruited from a department of Reproductive Medicine in a central London teaching hospital. Staff in the donor insemination clinic gave their support to the research, allowing, in the early stages of the research, observation of some of their consultations with patients.

The clinic is set within a reproductive medicine unit, which offers other general fertility treatments (such as ovulation induction and intrauterine insemination) and at

the time of research was seeing 70 couples for DI treatment. However some of these couples were taking a break from the treatment, or were in the middle of further investigations.

Typical steps taken by a couple considering DI are described below: A referral to the clinic is usually precipitated by a visit to their GP. After initial meetings with the consultant at the clinic, investigations may be carried out and a sperm sample taken from the male partner. It may be at this point that the couple receive a diagnosis and given results of investigations the likelihood of conceiving using the man's sperm is assessed. In some cases if there are also female causative factors IVF (In vitro fertilisation) may be combined with DI. However this is not a treatment currently offered at the clinic used in this study. Following investigation, suitability for treatment is assessed and the DI process explained to the couple. If they wish to proceed with treatment a session of 'implications counselling' (a standard requirement following HFEA legislation in 1990) is carried out where the couple discuss with a nurse, doctor, or counsellor the implications of DI for themselves and any future child.

At the clinic used in this study each couple is offered up to 12 cycles of DI treatment, however if, after 6 cycles a pregnancy has not been achieved the couple may undergo further tests, or additional treatments such as ovulation stimulation. The clinic estimates that 50% of couples treated become pregnant after 6 cycles. This is in accordance with the Royal College of Obstetricians and Gynaecologists who estimate that one half of couples undergoing DI treatment will become pregnant after 5 treatment cycles (RCOG 1992).

DI Network

The DI Network is a support group comprising individuals and couples who are considering DI or have undergone treatment with donated sperm or eggs. The network was first set up in 1993 and started by parents who had decided to tell their children about their origins. At present members include married and unmarried couples, single women, lesbian couples, parents who are now separated, divorced or widowed and individual adults who are donor offspring.

The majority of members with children choose to be open about DI. Newsletters are sent and regular meetings are held to facilitate mutual support. At present the Network has nearly 300 members (each member being one 'household'). They are active in promoting interest in DI and two members have recently produced a book called 'My Story' (Infertility Research Trust 1991) which is designed to be read to a child born as a result of DI.

2.3 Ethical Considerations

The UCLH committee (see Appendix 1) gave ethical approval. An information sheet and consent form were also drawn up and approved (see Appendix 2 & 3). Recruitment letters (see Appendix 4 & 5) were designed for the two different settings (clinic and DI Network) and also approved by the UCLH ethics committee.

2.4 Participants

Inclusion Criteria

Clinic Sample - Data were collected from all couples who either had or were having DI treatment. All couples were approached except those who did not speak English fluently.

DI Network - All members of the DI network who were either currently having DI treatment or who had completed treatment successfully, and were in heterosexual relationships were invited to participate.

2.5 Procedure

Hospital clinic sample

Due to both clinic policy and issues of confidentiality the researchers did not have access to the files directly. Therefore the clinic staff sent letters to all those couples in treatment (70) inviting them to participate in the research. All were reassured that their participation would in no way affect their treatment or care. If couples were willing to participate they returned a small slip with basic information to the researchers directly (i.e. they opted into the study). Questionnaires, consent forms, information sheets and a stamped addressed envelope were then sent to participants. Reminders were later sent out to those who had expressed interest but who had not returned their questionnaires.

DI Network Sample

Recruitment involved meetings at early stages in the research with members of the network and their own research steering group.

DI Network members were approached via their autumn newsletter. A piece written by members of the network research group appeared in the newsletter which encouraged members to take part, and gave the research their support (see appendix 6). A recruitment letter and stamped addressed envelope was enclosed with the newsletter that went to the 280 members of the network (280 households). Interested members then returned a slip directly to the researcher (NSL). Their name, partners name, treatment status and address were the pieces of information they supplied. Those who wished to participate anonymously could do so by requesting a questionnaire directly from one of the Network research steering group members rather than from the researchers, thereby avoiding giving their personal details.

104 households (37%) returned the slips indicating they would be willing to participate. Questionnaires were then sent to each (1 per member of the couple), a consent form and information sheet were also enclosed.

The researchers telephone numbers were also provided so that participants had the opportunity to discuss any concerns they had about the research.

Response rate from the hospital clinic sample

Of these 70 couples receiving treatment 25 (36%) returned reply slips indicating they would be willing to participate. However, of those 25, 12 (48%) couples returned their questionnaires and one woman returned hers although her partner did not. All 13 women and 12 men were included in the study, all were currently receiving DI treatment.

Response rate from the DI Network

A total of 280 recruitment letters were sent (i.e to 280 households). However, this included all members, some of whom did not meet the inclusion criterion for the study. One hundred and four households (37%) returned the slips indicating they were willing to take part. Out of those 104, 64 (61%) households returned their questionnaires.

These households were made up of 103 people who were all included in the study. Nine men and 11 women were currently in treatment and 39 men and 44 women had completed treatment and now had a child.

2.6 Measures

The Hospital Anxiety and Depression Schedule (HADS: Zigmond & Snaith, 1983)

(see Appendix 7.)

The HADS was developed for use with non-psychiatric hospital outpatients. Respondents are asked to indicate how they have been feeling in the past few weeks on a four-point scale. (E.g.: I feel tense or "wound up" - most of the time, a lot of the time, occasionally and not at all)

Scoring the HADS gives a separate score for anxiety and depression and each item is scored 0, 1, 2 or 3 according to degree of severity. Zigmond and Snaith gave two cut-off points for "caseness" of anxiety and depression. A cut-off of 10/11 is used to reduce the number of false positives whilst a lower cut-off of 8/9 was suggested if the priority is to include all possible cases of psychiatric morbidity.

This screening scale for anxiety and depression contains 14 items and has been well-validated (Zigmond & Snaith, 1983).

The Fertility Adjustment Scale (FAS: Glover, Hunter & Richards, in press) (See Appendix 8)

This scale was recently designed to assess adjustment to fertility problems.

It is a self-assessment screening scale containing 12 items, which cover the individual's reactions to their fertility difficulties and treatment. In particular it focuses on the extent to which the person has come to terms cognitively, emotionally and behaviourally, with the possibility of not having a child.

Participants are asked to rate themselves on a number of statements such as: "I will continue with investigations/treatment until I succeed in having a child" and "I seem to live my life month to month". They then rate themselves on a 6 point scale of agreement (1 = strongly disagree, 6 = strongly agree).

When scoring the FAS the total score is taken by adding each response to gain an overall adjustment score. A high total FAS score is taken to represent poor adjustment; scores could range between 12 – 72. Where the FAS has been used with men and women undergoing other fertility treatments (IUI or IVF) the mean score for men was found to be 39.1 (SD=10.3) and for women 39.3 (SD=13). There is as yet not enough data on this scale to define a clinical cut-off, although a score of 39 or higher would suggest difficulties in adjustment.

This scale is still in the early stages of being piloted with different groups but has been shown to have good reliability and validity (Glover, Hunter & Richards, in press).

DI Study Questionnaire

A questionnaire was designed specifically for this study. It included a number of questions about the treatment and implications counselling received. For those couples who have a child or children through the use of DI a section was included on 'telling your child' inviting them to write a short description of how they plan to tell or told their child.

Questionnaire for the clinic sample (see Appendix 9)

1 (i) Demographics

This included questions regarding age, work status, ethnic origin as well as a number of questions focused on treatment (number of cycles received so far, diagnosis, how long in treatment)

1 (ii) Distress

Participants were also asked to rate their level of distress and that of their partner on a scale from 1-10. e.g:

"Please circle a number on the scale below to show how distressed you feel at present about you and your partners difficulties in having a baby?"

A rating scale was also included for participants to rate the extent to which DI treatment interfered with their daily routine and lifestyle. Space was left for them to write about this in more detail if they felt it had interfered.

1 (iii) Concerns

A number of 10 point scales were included which covered concerns one anticipated relevant for those undergoing or having undergone donor insemination.

Participants were asked to rate how concerned they were at present about a number of issues. For example the issues included, telling the child, telling family, the

medical procedure of DI, risk of multiple births and donor match. There were also scales focusing on the impact of DI on the relationship with your partner and worries about relationship with any future child.

Participants were asked to describe their concerns that related to their fertility difficulties and the DI treatment in response to an open question.

1 (iv) Counselling

This section covered the counselling needs of the participants asking them to tick the issues they recalled the doctor discussing with them. This list contained all issues, which are recommendations for implications counselling sessions such as the pros and cons of telling the child and family about DI, the process of matching donor and male partner, and the opportunity to talk about feelings.

Participants were also asked if they would like counselling, and if so with their partner or on their own.

1 (v) Telling the child and others

Participants were asked to state whether they planned to tell a child that they might have as a result of DI treatment about his/her origins; we also wanted to know the reasons they had for their decision on telling or not. Participants were asked who else they had told about their DI treatment (friends, family, employer, work colleagues) and what their reaction was. An option was also included for those who had told no one.

1 (vi) Conclusion

Finally, space was left on the questionnaire for the participant to write a more qualitative account of their treatment. This included asking the participant to rate

how likely they feel it is that they will conceive through DI (on a scale from 1-10) and also if their experience of DI treatment was better/same/worse than expected.

The HADS and FAS were attached to the questionnaire.

Questionnaires for the DI Network

Network members currently having treatment (see Appendix 10)

These participants received questionnaires, which were almost identical to that described above. However, the front sheet of the questionnaire made reference to the network and emphasised that if they had more than one child resulting from DI treatment, they should think only of their current treatment when answering the questionnaire. The HADS and the FAS were attached.

Network members whose family is complete (see appendix 11)

This questionnaire was used for those who had finished treatment and had conceived a child through the use of DI. Participants were asked to fill in the questionnaire considering their feelings at present and thinking back to their most recent experience of DI. It was similar to the questionnaires described above.

2 (i) Demographics

The demographic section was identical, but also asked the age of the child the participant had had most recently through DI.

2 (ii) Distress

The distress section was identical but asked people to rate their distress at present rather than thinking back to when they were having treatment. However they were still asked to rate how much they felt DI interfered with daily life when in treatment.

2 (iii) Concerns

This section was identical but excluded the questions about treatment (e.g. multiple births, getting pregnant and the medical procedure)

2 (iv) Counselling

This section was similar, including all the issues that should be covered in implications counselling. In addition, these participants were asked whether they had seen a counsellor.

2 (v) Telling the child and others

More space was allotted to this issue as it was felt that it was likely to be a more pressing topic for those who now have a child. If the participant stated they planned to tell their child and had done so they were asked to write a brief account of this and any ensuing difficulties they or their child had experienced.

As in the treatment questionnaire participants were asked to state who they had told about DI and their reaction.

2 (vi) Conclusion

The final section on the questionnaire was the same, leaving some space for more qualitative data and overall feelings about DI and fertility difficulties.

Only the HADS was attached to the questionnaire, as the FAS was no longer relevant for those individuals/couples.

2.7 Analysis

Results from scales on the questionnaire, the HADS and FAS were analysed using the Statistical Package for Social Scientists for Windows 7.01 (1995 SPSS).

As explained in the results section the clinic sample and the DIN 'in treatment' sample were combined to make one 'treatment' group. The two groups, those in treatment and those who had completed their families were then examined separately. Qualitative data was explored and common themes drawn out to provide some insight into other areas such as 'telling your child' and common concerns about treatment. Content analysis was then carried out on the qualitative data. This involved establishing categories for the issues covered in the questionnaires (such as how you told your child) and counting the number of instances when these categories are used. These categories were rated and checked by another psychologist. In addition textual qualitative data was combined with simple word counts.

CHAPTER THREE

RESULTS

“I felt the path of DI was quite a lonely one and that the professionals lacked the human touch. It went on for a long time, we have experienced 22 cycles of treatment in all” (Woman, who now has a child through DI)

“The stresses of a new baby are actually pleasures e.g.. Waking in the night to feed/comfort your child is such a joy after years of waking in the night, crying because there was still no baby”. (Woman who now has a child)

A. COUPLES UNDERGOING DI TREATMENT

3A.1 Sample characteristics: couples in treatment

Because of the low response rate from the clinic sample a preliminary analysis was carried out on the two treatment groups (clinic and the DI Network) to examine whether there were any significant differences. Similarities and differences in socio-demographics, distress measures and treatment status are shown in Table 1.

Table 1. Similarities and differences between the treatment groups (clinic and DIN)

	Clinic (N=25)	Sample	DI Network Sample (N=20)		Mann-Whitney U	
	M	SD	M	SD	U	
Age (years)	33	(5.57)	32	(5.09)	208.5	NS
Length of time in treatment (months)	26.52	(17.72)	21.70	(11.17)	207	NS
Number of cycles so far	8	(5.97)	5.3	(3.51)	162	NS
Distress rating	7.26	(3.38)	7.25	(2.46)	203	NS
HADS anxiety	8.95	(4.81)	8.90	(4.32)	209	NS
HADS depression	3.90	(3.63)	4.55	(3.30)	176	NS
Total FAS score	48.78	(7.75)	49.4	(7.56)	215	NS

U = Mann Whitney test value. NS= not significant

Distress measure = 1 (not at all distressed) – 10 (very distressed)

HADS anxiety and depression scale = 8/9 borderline score for caseness.

FAS score = scores can range from 12-72. Mean of earlier study =39.

Table 2. Ethnic and educational status of the two ‘in treatment’ groups

Sample	Ethnic status White	Ethnic status Other	Left education at age 16	Continued education after age 16
Clinic sample (N=25)	22 (96%)	1 (4%)	13 (56%)	8 (34%)
DIN sample (N=20)	20 (100%)	0	2 (10%)	18 (90%)

This preliminary analysis of the two groups in treatment revealed that they did not differ significantly on socio-demographic variables, except age of leaving full time education ($\chi^2(1)=11.23, p<.01$). On variables such as age, ethnic background, length in treatment and the four distress measures they did not differ significantly. For this reason the groups were combined and the male and female differences examined. Combining the groups is perhaps justified as it allows a range of educational status to be present in the whole treatment group. Although this research decision has its problems it provides a group large enough to examine gender differences and some of the differences between the clinic and DIN treatment sample. The implications of these are drawn upon later.

3A.2 Demographics of treatment sample

Twenty-three women and twenty men participated who were all undergoing DI treatment. This sample comprised twenty couples and for some of the analysis of

results they are discussed together as couples. Gender differences are examined taking account of all men and women; all were in heterosexual relationships.

There was a significant difference in age between the men and women in treatment. (The mean ages of the men and women were 35 years and 31 years respectively $U=132$, $p<.05$). Forty-two (98%) out of the 43 participants reported their ethnic status as 'white', and one as 'Mediterranean'.

Seven couples (32%) reported having had a miscarriage during treatment, 6 of the miscarriages were during DI treatment and one was after a 'natural' pregnancy. Eighteen (41%) people had other children during the time when they were participating in the research. Out of these children, 12 (66%) were born as a result of earlier DI treatment and 6 (33%) without treatment (from earlier relationships or prior to a vasectomy).

The following reasons were given by men for their fertility difficulties: seven men (35%) had difficulties with their sperm count or motility, six men (30%) reported being azoospermic, five (25%) had a genetic condition and two men (10%) had attempted a vasectomy reversal operation which had been unsuccessful.

The couples in treatment reported having tried for a baby for an average of 51 months ($SD = 29.20$) and had first attended the clinic for treatment 24 months ago ($SD =15.06$). Couples had received on average, 6 treatment cycles ($SD=5.12$) so far and had waited on average 14 months ($SD =14.24$) before attending a clinic for DI.

3A. 3 Research Question 1.

What are the concerns of men and women undergoing donor insemination treatment?

Couples in treatment rated DI as interfering into their daily life to quite an extent, (1=interferes not at all, and 10=interferes very much). Women rated the level of interference into their lives as significantly higher than men (means for women and men were 7.65 and 5.60 respectively, $U=142.5$, $p<.05$).

The reasons for interference were as follows: Five men (25%) felt that travel was a factor, only two women (8%) felt that travel was a problem. Three men (15%) stated that the treatment dominated their mind, making it difficult to carry on normal life. Five women (22%) also stated that they found this difficult. Three men (15%) and four women (17%) found it difficult to get time off work. Two men (10%) and three women (13%) found the DI treatment made it difficult to plan the future. Two men (10%) stated that having DI made them feel abnormal or different, thus preventing them from functioning as usual, and one woman (4%) also stated this. Other reasons given by women were the difficulties in arranging appointments around their ovulation (3/13%), the effect of worrying and stress every month (3/13%). One man (5%) also commented on the difficulties of arranging to get to appointments around his partners ovulation, one man commented on the financial implications of treatment and one man and one women added that the IVF treatment they had tried had interfered far more than the DI treatment.

Two quotes illustrate the difficulties listed above:

“Attending the clinic, psychological pressure every cycle, has this worked? What can I do to influence it working? Should I shower, swim, walk, bath, drink, etc. - everything feels as if it could have an effect and life is on hold.” (Woman in treatment)

“It seems to dominate your life everything has to revolve around the treatments. The tension builds up to a head at the end of my wife’s cycle. If her period starts then her disappointment and stress is very evident, and of course it affects myself.” (Man in treatment)

Table 3

Men’s and women’s ratings of concern regarding aspects of DI treatment

	Men		Women		U
	M	SD	M	SD	
Getting pregnant	7.25	3.41	8.73	2.68	166*
Donor characteristics	5.80	3.07	5.00	3.01	195
Telling the child	5.30	3.29	5.34	3.12	224
Effect of DI on relshp	5.15	3.39	5.52	3.48	214
Matching the donor	4.70	2.63	5.21	3.01	207
Child’s right to seek info	4.50	3.33	5.21	3.32	202
Telling the family	4.10	3.29	3.91	3.21	215
Appearance of child	4.05	3.06	4.00	2.87	227
Multiple births	3.60	2.92	2.82	2.34	196
Medical procedure	3.25	1.99	3.39	2.40	228

*p<.05

Note. All variables were rated on a 10-point anchored scale ranging from 1= not at all to 10= very concerned.

From Table 3 it is evident that the aspect which most concerns men and women in treatment is achieving a pregnancy. Other issues felt to be important at this stage are those about the donor, his characteristics and the match between donor and male partner. A concern is also expressed at this stage about telling the child. There is also quite a significant concern that DI has an impact on the relationship with your partner. There was a significant difference between how men and women rate their level of concern about getting pregnant, with women giving higher ratings.

Content analysis was carried out on comments made by men and women on the most difficult aspects of DI treatment. Results are shown in table 4.

Table 4 The most difficult aspect of DI treatment for men and women

Most difficult Aspect of DI	No of comments Made by women.	No of comments Made by men
Secrecy/stigma of DI	23 (15%)	9 (10%)
Duration of treatment	18 (11%)	10 (11%)
Impersonal treatment	18 (11%)	9 (10%)
Emotional impact of DI	16 (10%)	8 (9%)
Relationship issues	6 (4%)	13 (15%)
Disruption to daily life	11 (7%)	8 (9%)
Medical issues	15 (9.5%)	2 (2.5%)
Feeling ‘abnormal’	14 (9%)	4 (5%)
Donor issues	10 (6.5%)	4 (5%)
Miscarrying	7 (4%)	1 (1%)
Male infertility issues	6 (4%)	9 (10%)
Actual insemination	6 (4%)	2 (2.5%)
Cost of DI	4 (3%)	3 (4%)
Lack of control	3 (2%)	5 (6%)
Total no comments	157	87

(The most common themes are shown in bold)

From Table 4 we can see that the issue that was found to be the most difficult for men was the impact of DI on their relationship with their partner. Men were also very concerned by the length of time they had spent in treatment, the secrecy surrounding DI and their fertility difficulties. The women expressed concern about the secrecy and stigma of DI treatment, and the length of time spent in treatment. There is a striking difference between men and women on their feelings about the secrecy and stigma surrounding DI. There were also a considerable number of comments regarding the medical aspects of treatment and feeling abnormal or different as a result of having DI. Women found the donor issues more difficult than the men, and similarly rated the future implications of having a DI child as more difficult than the men.

Some of the aspects of treatment found to be most difficult are those that are also applicable in other fertility treatments, such as the emotional impact, the duration of treatment, miscarriage risk and disruption to daily life. However many of the issues commented on also reflect those aspects which are specific to DI. These include the donor issues, the secrecy and the insemination with another man's semen.

These quotes illustrate some of the main difficulties with DI treatment (those in highlighted in the table).

The Secrecy and Stigma surrounding DI. Men and women commented on the difficulties in the DI field in terms of keeping it secret, dealing with others possible negative reactions and the fear of the stigma of DI.

“The general public should be better informed on the treatment so that there is less secrecy in telling children they are DI treatment children because of the stigma attached to it.”(man)

“Unlike other forms of fertility treatment once you have a child, the problems are not over, they are just beginning e.g. disclosure and other peoples reactions.” (woman)

Duration of treatment. Comments made on this issue centred on the emotional impact of ongoing cycles and failures each month. Many described their fear of remaining childless and of wasted time prior to treatment.

“I have menstruated pointlessly for 25 years. If this is not successful I am going to ask for a hysterectomy or the pill to stop my menstruation. I cannot be bothered with the monthly reminder of failure any longer” (woman).

“Very stressful waiting time then if your period starts and the treatment hasn't worked you have tears then start again”(woman)

The impersonal nature of the treatment. Many men and women commented on their experience of DI in terms of feeling unsupported by clinic staff. Some commented on feeling that the emotional impact of treatment was rarely acknowledged, and that it was at times a rushed and impersonal process.

“The slightly impersonal touch to it all. The fact that after receiving a treatment they can't get you out quick enough.. They lose touch with the women's emotions and stress.” (man)

“I felt like I was on a conveyor belt” (woman)

“The medical staff seem totally insensitive, particularly to my wife's reactions and feelings, the insensitivity and lack of emotional support from the medical staff.”(man)

Emotional impact of DI. This covered concerns about the effect of DI treatment on mood and levels of distress.

“I have no enthusiasm or drive to do things” (man in treatment)

“The psychological and emotional aspects of DI are far harder to deal with than the physical, as a result the monthly ups and downs are intensified” (woman in treatment)

Relationship issues. The men in particular commented a lot on the impact that DI had on their relationship with their partner. Couples described the tension and difficulties in their relationship through the monthly fluctuating emotions and pressures of treatments. Many commented that they felt that supporting each other greatly helped with the stress of treatment.

“Blaming each other and arguing. But we are strong now and it has been an experience”(man)

“Emotionally difficult, relating to each other, and waiting for something to happen.”(woman)

“Your relationship has to be very solid to come through the other side”. (woman)

Disruption to daily life. Comments made centred primarily on the difficulties of arranging appointments and negotiating time off at work.

“I would like to work part-time during what could be a long wait, but feel unable to combine my profession with necessary time needed for clinics and monthly ups and downs.”(Woman in treatment)

Medical Issues. In this section comments included those made about the medical management of their care. This covered drugs, consultations, fears of infection from the donor sperm and prior investigations.

“I get concerned about the scope for human error in the process, wrong sperm, incorrect tests, poorly defrosted sperm etc”. (Man in treatment)

“Infection, AIDS, if all sperm is screened, can this be missed?” (Woman in treatment)

Feeling abnormal or ‘different’. This was related to the stigma surrounding DI and the difficulties faced when unsuccessful in treatment. Many women compared themselves to their peers, and described the pain in seeing other people get pregnant without treatment.

“The most difficult thing is not being like everyone else and coming to terms with that is hard also it not working when you expect it to.”(Woman)

“Most of my friends ask ‘why don't you have a baby?’ and I can't tell them that it affects me and I don't see them now.”(Woman)

“We can't just go up-stairs and have a baby.”(Man)

“Very strong feelings of being left behind by our peer group and/or it will probably never work for us.”(Man)

Concerns about the donor. Men and women commented on anxieties they had about the use of donor sperm, who the donor was, and their motives.

“Donors, who are they? Students, tramps, doctors, old men?” (Man)

“I worry about things like have they mixed donor up and I've got a donor of a different ethnic background”(woman)

“I find it very hard not knowing who is the donor. I look at my son and wonder who the genetic father is. Knowing that somewhere else there is someone who might look like him”(woman who has a child already and is now in treatment again).

Miscarriage risk. Some expressed their concern about previous miscarriages or anxieties about this happening again.

“Most difficult is the repeated miscarriages, 5 so far, hopes raised and then dashed” (woman in treatment)

Male infertility issues. Comments made on this issue tended to focus on the difficulty of not being the genetic father of any child born as a result, men also spoke of feeling guilty and angry at the need to use DI. Some men also acknowledged that DI did not take away their fertility difficulties.

“I feel the future would be very bleak without children. I feel that one of the main reasons for existence is to reproduce genetically.”(Man)

“Coming to terms with the fact DI though costly, time consuming etc has not solved my infertility by only offered a way around it”(Man)

The Insemination. Women commented on the difficulties of the actual insemination, and the emotional impact of this as something they had not expected. Several men also described their feelings in this fundamental part of the DI process.

“I feel helpless and uncomfortable watching my wife have the procedure. “ (Man)

“Being treated like an animal for insemination rather than a person with feelings and concerns.”(Woman)

“I was so tense my first insemination hurt, but subsequent ones have not”(woman).

“First clinic was awful after each treatment I felt dirty and it was like a sleazy horrible thing the other clinic was the complete opposite, it was infinitely better and a very positive experience.”(Woman)

Lack of control. Men and women both commented on feeling out of control of their own body when undergoing DI treatment. This involved having to allow the clinicians to make treatment decisions, and lack of control over being able to get pregnant.

“I don't feel in control of any decisions anymore to do with my body”. (Woman)

“The fact it is so personal. I feel invaded, physically, emotionally and mentally”. (Woman)

“I bitterly resent a consultant telling us that we should not have let treatment go on for 9 cycles as if we had control of process; this blurring of responsibility is unprofessional and for us expensive, emotionally and financially.”(Man)

Women were more likely than men to rate their experience of DI as same or worse than their expectations, 8 men (40%) rated it as better than their expectations, whereas only 2 women (8.7%) did so. 6 men (30%) and 10 women (43%) rated DI as being the same as their expectations. 6 men (30%) and 11 women (48%) rated it as worse than their expectations.

3A.4 Research Question 2.

How do men and women differ in terms of distress, mood and adjustment when in treatment?

Table 5

Men and women's distress, adjustment and mood levels during treatment

	Men		Women		U
	M	SD	M	SD	
Cycles expected	7.84	4.04	8.59	3.81	186
Likelihood of conceiving	7.20	2.83	7.00	2.82	199.5
Distress re own fertility difficulty	6.20	3.05	8.17	2.60	126.5*
Partners distress	8.30	2.34	7.30	3.00	188
Total FAS score	49.10	6.70	49.04	8.42	228
HADS anxiety score	8.21**	4.36	9.54**	4.66	173
HADS depression score	3.31	2.70	4.50	3.86	153

*p<.05

** = Above clinical cut-off for borderline HADS anxiety score (8/9)

Both men and women expect to receive at least another 8 treatment cycles, bearing in mind on average couples have so far received 6. They rate it still quite likely that they will manage to conceive with DI (mean rating 7 out of 10).

From Table 5 women were shown as significantly more distressed than the men regarding fertility difficulties. Their mean rating from the men was consistent with the women's rating of themselves. However, the women rated their partners as more distressed than the partners rated themselves.

In terms of the FAS, the scores of this sample approach one SD above the norms (M=39) for samples of those attending a clinic for a range of fertility problems As

shown above both men and women are scoring at 49, which suggest that perhaps these patients are reporting greater difficulties in their adjustment. The sample also fall into the borderline score range for 'anxiety' levels for the HADS. Both men and women are within the non-depressed range for depression (HADS).

These quotes from qualitative data illustrate the emotional impact of DI on these couples:

“The emotional aspect of things i.e. two failed attempts and one aborted attempt both my wife and I cried bitter tears of helplessness and hopelessness” (Man)

“One or both of us are often feeling down, the feelings can hit you when you least expect and can last for days.” (Man)

“Until actually going through this myself with my husband I never would have imagined how low we or anyone could feel. I didn't realise how depressed I was until I felt better.” (Woman)

“I feel my life is empty, most of the time I dream of baby” (Woman)

3A.5 Research Question 3.

What are the counselling and information needs of couples in treatment?

Only two men (10%) stated they would have liked to see a counsellor, both said they would like to be seen on their own. Five women (21%) felt they would benefit from seeing a counsellor and three of them wished to be seen alone, and two with their partner.

Sixteen couples (80%) reported being given information about the donor in their session of implications counselling with the doctor/nurse/counsellor. Most were also given information on the medical procedure of DI (19/20 95%) however, there were differences in terms of other issues not being covered in implications counselling.

Only 7 couples (35%) recall discussing issues relating to telling your family about DI. Again only 7 couples (35%) discussed with the clinic the issue of how to tell their child about DI, 14 (70%) couples reported being given the opportunity to discuss their feelings about the treatment.

Only two men (10%) stated they would have liked to have had further discussion with the doctor, issues they wished to cover were success rates and the cause of their fertility difficulties. More women wanted further discussion with the doctor, 7/23 (30%). Issues the women wanted to raise were the treatment plan, success rates, information about the donor and how to access more support (e.g. the DI Network).

The following quotes illustrate the counselling needs: according to three themes that arose: needing counselling in the early stages of DI and wanting more contact with other couples in treatment. There was also some anxiety about feeling judged in implications counselling, perhaps related to the low interest shown in wanting counselling.

Needing counselling in early stages

“I am pleased that the HFEA have regulated treatments but still have concerns that husbands state they have 'accepted' their inability to make their wife/partner pregnant and clinics do not enforce counselling prior to commencing treatment. It is too late once a pregnancy from DI has been achieved!” (Woman)

“Counselling should be offered when you are told you are infertile, not months later when you have already decided on DI.” (Woman)

Wanting support from others in treatment

“I personally have found the support from ISSUE and DI Network invaluable. Information is what I have needed most, but contact with others in a similar situation and the knowledge that a helpline exists are also great comforts.” (Woman)

“I think one way to improve services would be to offer more hands on support from people who have been through what you are going through.” (Woman)

Being judged

“I felt as if my future was in counsellor’s hands. The doctor would use counsellor’s information in decision as to whether to treat me. So I felt everything I said was crucial although I didn’t really know what she wanted to hear. I did not like being judged as to my ability to be a good parent.” (Woman)

3A.6 Research Question 4.

What are the experiences for this group when telling others about DI and in making the decision whether to tell their child about his/her genetic origins?

It was in relation to the issue of intention to tell that the clinic and DI Network members differed most. This was expected as those who choose to join the Network are generally considering a more open approach to DI and telling others.

Table 6 Clinic and Network differences regarding ‘Intention to tell’:

	Plan to tell	Undecided /against telling
DI clinic	3 (13%)	20 (87%)
DI Network	20 (100%)	0 (0%)

This difference was statistically significant ($\chi^2(1)= 32.51, p<.001$)

There were clear differences between the clinic population in treatment and the DI Network members in treatment in terms of who they had told about the DI treatment.

There were differences in terms of reasons why the men and women had waited prior to their starting treatment. Three couples (30%) from the clinic gave the waiting list

as the main reason. Two couples (20%) said that they were having investigations. Two couples (20%) said they had just started new relationships, and one couple (10%) had miscarried, so had a period of grieving. One couple (10%) waited as the male partner was unsure about DI treatment.

Those couples from the DI network gave different reasons for their delay in starting DI treatment. Three couples (33%) stated they were unsure about treatment, three couples (33%) stated that they were coming to terms with their fertility difficulties before commencing on treatment. Two couples (22%) were on the waiting list, and one couple was having further investigations.

The clinic

In terms of the men, 7 out of 11 men (63%) had told their family, and only one man (14%) reported a negative reaction. Only two men (18%) had told work colleagues, and had received a generally positive reaction from both. Five men (45%) had told at least one close friend, and again all had responded positively.

Women attending the clinic had also told several people about their treatment. Seven women (58%) had told their family, all responding positively. Two women had spoken to their work colleagues, getting a positive reaction from all. More women had spoken to close friends with 7 (58%) and only one (14%) reported a negative reaction.

Eight people (34%) had told no one. Out of all those in treatment 4 women (17%) had not told anyone about their DI treatment, 4 men (their partners) had also not told anyone.

One person reported telling their GP.

Only 3 (13%) people planned to tell their child of its origins, 10 (43.5%) were uncertain and 10 (43.5%) thought they would not tell the child. As many of those who were uncertain raised negative feeling about telling, those who were uncertain and those who did not intend to tell were combined into one group of 20 (87%).

Network men and women in treatment

Men and women who belong to the DI Network were very different in their approach to who they told.

Seven out of nine men (78%) had told their family, only one reporting a negative reaction. Only one man had told a work colleague, but 8 out of 9 (89%) had told at least one close friend, again only one reporting a negative reaction. For the DIN women in treatment 10 out of 11 (90%) had told their family, one reporting a negative reaction. Three women (27%) had told work colleges, all of whom responded positively. Ten out of eleven women (90%) had told close friends, again all responded positively.

All those in the DI network 20 (100%) planned to tell their child.

From these results it is evident that despite a mainly positive response, there is still some risk of a negative reaction for those to decide to talk to others. The following quotes illustrate the different views of participants.

Reactions of others

“Its a shame its is so difficult for some people to discuss, however the more people I tell the easier it seems to get, less pressure” (Man)

“We have told nobody, from the outset we decided it was not anybody’s business but our own. The question (of telling others or the child) is not for discussion.” (Man)

Table 7. Reasons regarding intention to tell child

	DI clinic	DI Network
Telling disrupts child's happiness	5 (21%)	0
Need further advice before decision	7 (30%)	0
Don't believe in secrecy	1 (4%)	12 (60%)
Fear others might tell child	2 (8%)	4 (20%)
Fear child will want real father	1 (4%)	0
Child might not love father	1 (4%)	0
Unsure when to tell child	1 (4%)	0
Child will be mine, no need to tell them.	3 (13%)	0
Important for child to know their origins	0	3 (15%)

Other reasons given by the clinic population included; telling would unsettle and threaten the family, feeling it needed to be something agreed upon by both the mother and father.

Other reasons given by the Network population were that telling the child was essential for a good relationship with the child, a concern that they might be rejected by the child if they found out later; that telling avoided later problems and loss of trust or that there might be future possible medical reasons and that male infertility and DI were not issues to be ashamed of.

Those who are undecided or plan not to tell

*"I am concerned the child will find real father and not love me".
(Man)*

"My son does not need to know anything as there is nothing to know or find out, why upset a happy healthy child."(Man)

*"We have told nobody, I think it is best for the child they believe that the man that they have known as dad is their dad but if he did ask questions when older I might explain that he is special."
(Woman)*

“There is no point telling a child, it is a dead end story.” (Woman)

“I do not wish the child to feel different, or to jeopardise relationship between father and child.” (Woman)

Those who plan to tell

“It makes everything easier in the longer term. Keeping secrets is very tiring and destructive.” (Man)

“I couldn't cope with deceit over years. Much higher risk of rejection if child discovers origins as an adult. Whole family knows, wrong to keep from child itself. Possible medical reasons.” (Woman)

“I am reasonably confident about a good relationship between our children and my husband, but the DI aspect does sometimes concern me, mainly will the child love my husband as its father?” (Woman)

There was a significant difference between the group who planned to tell versus those who did not. Those who were undecided about telling their child were significantly more distressed about their fertility difficulties than those that were planning to tell their child. See table 8.

Table 8. Distress levels and concerns in the groups who plan to tell or are undecided

	Group who plan to tell child		Group who are undecided /not telling child		Mann-whitney value
	M	SD	M	SD	U
Level of distress	6.43	(3.14)	8.2	(2.48)	143*
Concern re telling your family	2.73	(2.32)	5.45	(3.53)	129*
Concern re telling the child	4.43	(2.59)	6.35	(3.51)	153*

* Significant at $p < .05$

Analysis revealed that those who were uncertain or wished not to tell were significantly more concerned about the issue of telling the child and telling their family on the rating scales.

However, as one can see above the majority of the clinic group (86%) was undecided about whether to tell their child, yet have already spoken to people about their DI treatment. This perhaps raises difficulties for the couples who decide not to tell their child yet know that others (family or friends) know so there is a risk that the child might find out accidentally.

There was a significant difference between those who plan to tell and those who were uncertain and their perception of DI treatment. Those who plan to tell their child were more likely to see their treatment as worse than their expectations (56%) whilst those who were undecided were more likely to see it as the same as their expectations (56%) ($\chi^2=12.46$ (2), $p<.01$).

B. GROUP WITH A DI CHILD, NO LONGER IN TREATMENT

3B.1 Demographics of group with a child

Of the sample from the DI network the total number of people falling into this category was 83 (39 men and 44 women and of these there were 39 couples). All were included in the analysis. The mean age of this group was 36, with men and women 41 years and 36 years respectively. Men were significantly older than women ($U=522$, $p<.01$).

The mean number of cycles people had received in order to achieve a pregnancy was 5.81. (SD= 4.92). 5 people had miscarriages during their DI treatment. The mean length of time that couples had waited prior to seeking DI treatment was one year, 7 months (SD=29.20). Prior to seeking treatment couples had been trying to have a baby for on average 2 years, 5 months (SD=31.84).

Male participants stated they had been given the following diagnoses: 16 (41%) men gave reasons of poor sperm quality/motility, 11 (28%) men stated the difficulty was due to being azoospermic. 7 (18%) people gave the reason of a failed vasectomy reversal and 1 (2.6%) had had testicular cancer in the past. Another 2 (5%) had congenital abnormalities and 1 (2.6%) had combined female and male fertility difficulties. One man (2.6%) had a genetic condition.

The ethnic background of the participants was predominantly white, with 81 (97%) reporting themselves as 'white'. One man (1.2%) was Mediterranean, and one woman was Jewish.

32 couples (38%) had other children at the time that they went for their last DI treatment to have another child. Of these couples, 24 (75%) had used DI in order to have earlier children, 6 (19%) had other children without using any treatments, and 2 (6%) had other children who were born both with and without the use of treatments.

In terms of work, 34 men (87%) were working full-time, 2 (5%) were studying, or responsible for child-care and one (3%) was working part-time. 11 women (25%) were working full-time, 19 (43%) were responsible for child-care and 14 (32%) were working part-time.

10 people (12%) had left full-time education at age 16, whilst 69 (83%) had continued on, gaining further educational qualification. This is consistent with the DIN sample in treatment. There was a significant difference between men and women in how much they felt DI interfered with their daily life style, when they were undergoing treatment. Mean rating for men was 4.22 (SD=2.61) whilst women rated it at 6.43 (SD=2.91). This difference is significant ($U=511, p<.01$).

All planned to tell their child/children if they had not done so already.

3B.2 Research Question 1.

For those men and women who now have a child, what are current levels of distress and mood?

Table 9 Men and women's current distress and mood levels

	Men (N=39)		Women (N=44)		Mann-Whitney
	M	SD	M	SD	U
Distress regarding fertility difficulty	2.56	(1.69)	4.00	(2.73)	593*
Partners distress	3.89	(2.67)	3.83	(2.29)	818
HADS anxiety	5.00	(3.47)	7.09	(4.28)	565*
HADS depression	2.54	(2.43)	2.85	(2.33)	698
Expected cycles	5.51	(2.39)	6.81	(3.10)	627

Distress rated on scale 1-10 (1= not at all & 10= very distressed)

Expected cycles on range from 1-13+

* = significant at p<.05

On examination of Table 9, women were significantly more distressed regarding the fertility difficulties than the men. Women were also shown to be significantly more anxious than men, falling in the borderline range.

Reasons given for waiting prior to starting DI treatment were as follows; 8 couples (23%) waited due to being uncertain about the DI treatment, and 8 (20%) were also waiting so to have a good age gap between their children. Seven (18%) people were having investigations, 5 (13%) stated they were coming to terms with their infertility. Three people (7%) were trying other treatments such as IVF or IUI, 3 (7%) were on a waiting list. Other reasons given were that two couples (5%) were waiting as the

male partner did not like the idea of DI. Two couples (5%) had miscarried and were having a period of grieving and one couple (2%) was waiting until they had stopped breast feeding their first child.

Emotional & psychological upset

“Giving up was difficult, after the third miscarriage when our child was 1 year old. I had to try to deal with both the grief of losing our baby and the grief of never having the second child we wanted so much - double grief.” (Woman)

“You become addicted to it, just one more month and so on. You become obsessed by it and of course your body and monthly cycle are a continual reminder every single day.” (Woman)

“I feel that infertility is a profoundly painful, lonely and difficult problem. As a young couple I think we found the process isolating and stressful”. (Woman)

3B.3 Research Question 2.

What are the concerns for men and women regarding DI once they have had a child/ren?

Table 10 Concerns on the rating scales

	Men (N=39)		Women (N=44)		Mann Whitney
	M	SD	M	SD	U
Telling the child	4.79	2.44	5.50	2.62	708
Child’s right to seek info	4.41	2.95	5.97	2.88	599*
Matching the donor	3.34	2.87	3.72	3.05	795
Donor characteristics	2.80	2.44	3.75	2.80	684
Telling family	2.74	2.76	2.52	2.67	799
Effect on relshp with partner	2.74	2.44	2.97	2.65	799
Appearance of child/ren	2.56	2.19	2.40	2.32	790

Ratings were made on a scale from 1-10 (1=not at all concerned, 10= extremely concerned).

* = p<.05

From the Table 10 we can see that the issues shift after having a child to concerns about the child’s future. Overall the ratings on the scales reflected fewer concerns than for couples undergoing treatment, ‘telling the child’ and the ‘child’s right to information’ being the most commonly rated concerns. This is illustrated by the following quote from one of the participants:

“I think treatment issues are very important whilst you are having treatment or contemplating it in the future. However once you have completed your family the issues change to telling children about DI and worries anxieties that they may have.” (Woman)

Table 11 Men’s and women’s concerns regarding DI

	Men’s Concerns	Women’s Concerns
Future implications for child	9 (23%)	9 (20.5%)
How to tell the child	4 (10.%)	12 (27.3%)
Donor issues	4 (10. %)	6 (13.6%)
Fear of others negative reactions	3 (7.7%)	2 (4.5%)
Lack of control over body	3 (7.7%)	1 (2.3%)
Need for counselling	2 (5.1%)	3 (6.8%)
Impersonal treatment at clinic	1 (2.6%)	2 (4.5%)
Wanting another child	1 (2.6%)	2 (4.5%)
Psychological impact of DI	1 (2.6%)	2 (4.5%)
Secrecy re male infertility	1 (2.6%)	0
Fear that child will reject father	1 (2.6%)	0
Lack of NHS funding	0	1 (2.3%)

Main concerns are depicted in bold.

The main concerns expressed by participants are illustrated by the quotes below.

Future for child

“I am concerned our daughter will have identity problems in later life” (Woman)

"Guilt that our problem has been passed on to a child who will not know about half of his genetic background. This doesn't occur to me until after he was born." (Woman)

"I am worried my baby will feel odd when he reaches his teenage years, how will it affect him when he cannot find out who the donor is?" (Man)

Telling your child

"I am concerned about how my son will feel about his origins, I have kept a large box of information for him in the hope he will understand our position". (Woman)

"Initially I had reservations about telling my children about their origins. I think this was because it exposed me as an infertile man, I talked about this with my partner and have come to terms with it and feel good that we have told our children" (Man)

"My only concern is for the children to know and to accept how they were conceived". (Woman)

Concerns about the donor

"I am concerned about developmental anomalies, e.g. protruding teeth, wearing glasses, acne, and medical problems, intellectual status." (Woman)

"At the time the children were under one year old the obvious difference in their eye and hair colour to both myself and my husband which family and friends commented on." (Woman)

"Feeling we had found the right donor. In terms of knowing you have a wonderful husband and trying to find someone who matched up to him by perhaps if you're lucky a paragraph of vague information about his height, interests, profession." (Woman)

"I would like to have more information about the donors i.e. his occupation, interests, characteristics etc, I do not have any information at all about either donor and I feel this as a loss." (Woman)

Fear of others negative reactions

"We are Catholics and I am rather worried about how him sharing the news will go down in a catholic school, consequently he is going to a local state school" (woman)

"Concerned whether to tell my mother (now over 80 years old) who we have not yet told". (Man)

The most difficult aspect of DI

Applying content analysis to responses from the open questions on the questionnaire, the most difficult aspects of DI were revealed. However, they were found to be similar to those expressed by those still in treatment. The same issues of continual failure of treatment, emotional impact, male infertility issues, and the impact of DI on your relationship arose. There was a difference in the number of comments made about the impersonal nature of the treatment and of the experience of the insemination. Some quotes from participants on these issues are shown below.

Impersonal treatment. Women recalled the insensitive nature of the treatment, feeling that in many cases their feelings, or their partner's feelings were not acknowledged, there were 14 comments on this from women (13%). Men commented on this 13 times (14%). There seemed to be more of an emphasis on the power imbalance between doctors and patients.

"I felt like we were on a factory assembly line. Once the decision was made, the doctors seemed to take over the process with very little information flow, or regard to how we felt. Insensitive sums it up" (Man)

"Initially my husband who came to every appointments nearly, was hardly acknowledged by doctors, all attention was focused on me and he resented that." (Woman)

"Having a gut feeling that the DI clinic was incompetent but afraid to say anything." (Woman)

"We felt Drs time was precious after all he was doing a marvellous thing, sort of being God to many families, although we were not quoted many figures for success." (Woman)

The experience of the insemination. Six (7%) of the comments made by women described the insemination itself being difficult. Four (5%) men also described their feelings about the insemination and in seeing their wife undergo treatment.

“It would be nice if there was some way in which the male partner could be part of the process. It’s a very strange feeling to know that a baby is being created but that I can’t take an active part in the process.” (Man)

“The act of DI conception being clinical and loveless” (Man)

“I didn’t think I would mind being present at the actual insemination but I found it to be a very upsetting experience, one I wouldn’t repeat.” (Man)

“(Most difficult) that it was not my husband. I felt it was very invasive the actual steel thing in my vagina. Horrible and painful.”(Woman)

“For me it was vital that I like the person/Dr who inseminated me, on one occasion I did not and it was a horrible experience.” (Woman)

“I felt I was betraying my husband although he was sure we were doing the right thing. The insemination process was psychologically upsetting” (woman)

Of those couples whose family are complete 16 women (36%) and 13 men (33%) stated the overall experience of DI treatment was better than expected. Thirteen women (30%) and 17 men (44%) felt it was the same as their expectations. Fifteen women (34%) and 9 men (23%) felt it was worse. From this we can see that women were more likely to rate the DI treatment as worse than their expectations than the men.

3B.4 Research Question 3.

Looking back on treatment what were the couples counselling and information needs?

Sixty-one (73%) people felt they needed more information about DI, 22 (26%) felt they did not. However, only 29 (35%) felt they would have valued more time discussing DI with the doctor, 54 (65%) felt they did not. Those who wanted more information wanted to talk about the following topics; longer term concerns about their children (16, 19%) the child's feelings about their father (2, 2.4%) and the need for more open discussion on the subject (2, 2.4%). Five people also wanted to discuss the opportunity for meeting with other couples undergoing DI.

Table 12

Implications counselling issues discussed

Issues covered by clinic	Issue was discussed	Issue was not discussed
Info on donor	61 (73%)	22 (26%)
Info on medical procedure	74 (89%)	9 (10%)
Info on telling families	28 (33%)	55 (66%)
Info how to tell the child	27 (32%)	56 (67%)
Opportunity to talk about feelings	49 (59%)	34 (41%)

It is evident from Table 12 that whilst practical aspects of DI are covered in implications counselling, the majority of couples did not recall receiving information about telling. A significant proportion (41%) also felt that they were not given the opportunity to discuss their feelings.

When exploring the counselling needs of this group, 39 (47%) people stated they had seen a counsellor, 16 (19%) had not, 27 (32%) had seen a counsellor once for their one implications' counselling session. Counselling sessions took place before DI treatment in 49 (59%) of cases, after DI for 11 people, 17 (20%) had counselling sessions before and after their DI treatment. Only 3 people had received counselling alone, 59 had a session with their partner and 4 had received a combination.

The mean number of counselling sessions received was 3 (SD= 5.89, the range being between one and 24 sessions).

Other information requested concerned the following; 5 wanted information about telling their children, 5 about getting the same sperm for siblings, 4 people felt they needed more psychological support and 4 wanted information about other clinics. Four people raised issues about the donor and one expressed a view that the implications' counselling was inadequate. Requests for further discussion with the doctor centred on accessing more support, for example, wishing they had been put in contact with the DI Network sooner.

The following quotes illustrate some of the counselling needs of this group:

"The abiding memory is of a lack of counselling help at any stage. The nursing staff are obviously very busy and therefore don't have the time. At no stage was counselling readily available or offered and we are still aware of this being a problem." (Man)

"Initially knew I could not go through with DI, could not stand the thought of another man's sperm inside me. After 7 months of tears, talking to husband, friends, counsellor and DI network members knew it was for me. Have no regrets." (Woman)

"There is not enough counselling to ensure the issues are considered before going ahead." (Woman)

“We had several sessions with counsellor before treatment. We both felt they were very valuable and made us think about issues we would not have thought of on our own.” (Woman)

3B.5 Research Question Four.

Is there a relationship between proximity to treatment and levels of distress and effect on mood?

Proximity to treatment was measured by using the age of the most recent (youngest) child in the family. The mean age of the most recent child of these families was 2 years three months (SD=2.53). The age of the children ranged from eleven weeks to 15 years with few children older than four years. Because of this skew in the sample, correlations between age of the youngest child (i.e. proximity to treatment) and distress and mood were not performed. Instead four groups were compared: families whose youngest child was (1) one year or younger, (2) one to two years, (3) two to four years, and (4) school aged, i.e. five to 15 years.

A one-way ANOVA was then carried out on the data. No significant results were found. Comparisons between groups on the distress measure were $F(3) = 1.68$, on the HADS anxiety scores $F(3) = 1.42$ and HADS depression scores $F(3) = .522$.

This indicates that there are not significant differences depending on proximity to treatment and levels of distress, or effect on mood.

3B.6 Research Question Five.

What are the main concerns for men and women about telling their child/ren and what has been their experience of telling?

Most of the couples who have had children have spoken to others about DI.

Out of the men, 34 (87%) had told their own family, of whom 27 of the families (79%) reacted positively and 7 (20%) had reacted negatively. 33 men (84%) had told a close friend and only one (3%) had reacted negatively. 10 men (25%) had told their boss and received positive reactions from 8 of them (80%), negative reactions from two (20%). Six men (15%) had also told their child's school and all had reacted positively.

Only one man had told nobody.

Thirty-nine (88%) women had told their family and 33 families (84%) had reacted positively, and 6 (15%) families reacted negatively. Thirty-seven women (84%) had told at least one close friend, and of these friends 34 (91%) had reacted positively and 3 (9%) reacted negatively. Twelve women (28%) had told their boss, all reacting positively and eight had told their child's school, all again reacting positively. All the women surveyed had told at least one person.

In addition to the above information two women reported telling strangers such as taxidrivers and hairdressers.

Other's reactions

"Everyone we've told is firstly fascinated, then sympathetic, then totally accepting, maybe we're just lucky." (Woman)

"They have been most supportive in most cases although my partner's parents never discuss it ever." (Woman)

*“They were all told after the treatment and their reactions were surprisingly subdued, they were very surprised but it did not seem to have a huge impact that we imagined, they were very accepting”
(woman)*

“I tell strangers, such as hairdressers! Sympathetic, interested, many people forget all about it after a while and some slip into making comments about my child's appearance and who he takes after.” (Woman)

The reasons why men and women felt they should tell their child were as follows: 12 (31%) men and 16 (36%) women felt that family secrets were damaging.

Seven (17%) men and 10 (23%) women felt that it was important that the child should know their origins. One (2.6%) man and 2 (4.5%) women felt that as they had told others there was a fear that their child might find out inadvertently.

Three (7%) men and one (2.3%) woman felt that by telling the child and being honest this would ensure the child's future happiness and sense of security.

Out of the 83 couples surveyed 33 (40%) had already told their child, 50 (60%) had not yet done so and were waiting for the right time, or when the child was older etc.

The mean age of the child of those couples who had told their child was three years six months (SD= 3.51) The age range of the children who had been told was between 3 months and 15 years. Of those couples who had not yet told their child the mean age of the child was 1 year 5 months (SD=.93). The age range of these children was between 11 weeks old and four years of age.

The experience of telling

Couples responded to open questions asking about how they told their child/ren or feelings about planning to do so. There were a total of 40 and 81 comments made on

this subject by men and women respectively. Overall it is clear that deciding to tell one's child is not without its difficulties.

The following extracts illustrate the seven main themes identified:

How I have told my child.

Women made 18 (22%) comments on this, whilst men commented on this 7 (17%) times. Couples, who had told their child about the DI treatment, explained a little about how they did this. Many found ways to make 'telling' personal and to adapt the process to their child's level of understanding. The 'My Story' book was often relied on and made personal to the child, for example with family photographs. In most people's accounts, there was an emphasis on making sure the child understood how 'special' and wanted they were.

"I've also told the older one now since he was 6months, he now knows he's special and enjoys the story for the second one. I've followed my wife's line and added in extra material about the same kind man who gave us seeds to make D.(child)" (Father of a three and under one year old)

"It was mostly done by my wife. The idea was first introduced when he was a bit over 5, reinforced when he was about 7 and filled out completely when he was 10." (Father of a fifteen-year-old)

"My daughter asked at aged 3, we read a book she seemed interested then said oh I see, can I have fish-fingers for tea? So we now simply mention it in passing, she has begun to inform our 4-year-old." (Mother of a seven and four year old)

"If we had known about the book my story when he was four of five I would have started then. A bit young for him now we told him and obviously he cried because he was upset that his daddy wasn't his real daddy, but it was the initial shock. He asked a lot of questions over a two-week period. I think it was half term so this was useful, as we did not want school to know really." (Mother of a nine-year-old, told recently)

“One summer we grew sunflowers and I explained that (her dad) had no seeds to grow a baby in mummy's tummy so another very kind and special man gave us some, we planted them in my tummy and that is how she grew. She understood this though the planting of the sunflower seeds which we watched grow. I have told her from very young and before she could fully understand” (mother of a five year old)

“Attempted to tell my son. Asked him who he thought his father was and he said "dad". Then had to explain that we had a problem with seeds and that kind of thing. Related our problem to the cat who could not have kittens.” (Mother of a fifteen-year-old)

“We introduced our eldest son to the book ‘My Story’ at 3 years old. We had compiled a photo album with photos of me pregnant and the ultrasound scan, first photos when he was a few minutes old with both of us present and then photos of his first two years, happy family moments.” (Mother of a three and one year old)

Making it a natural part of the relationship with your child.

Women made 17 (21%) comments on this and men 6 (15%) times. Many couples discussed the difficulties of trying to make the information for their child as ‘normal’ and a ‘relaxed’ part of conversation. This was contrasted for some couples with the feeling that it would be a shock for the child to find out as if it is a major piece of news. It seemed easier for those couples who began this process earlier on in their child’s life.

“It only arises in general conversation – you’re special because.. We don’t make a major issue of it.” (Mother of a seven and four year old)

“It’s a difficult balance of bringing up the subject occasionally, or grabbing any opportunity as it suddenly arises, and not over emphasising it to make him feel unusual. It has to seem the most natural thing in the world.” (Mother of a one-year-old)

Worry about the child becoming stigmatised.

A number of men and women were concerned about the stigma of DI for their child, men and women commented on it 8 (20%) and 13 (16%) times, respectively. For

some couples there was a worry that by having shared information about the DI with the child that they would then draw attention to themselves. Some people discussed the fear of how it might come out at school, or how their child's friends reacted.

"Whenever a pregnant mother comes to our house I wonder if he's going to start explaining how he was conceived to them which creates some anxiety for me." (Mother of a three-year-old)

"Difficulties in the past were that he might say something and make himself vulnerable. This I think is an exaggerated fear but it does not stop parents worrying about the different status of their child. Felt I was worried about this and it did make me more anxious than possibly I would have been." (Mother of a fifteen-year-old)

Does telling threaten the relationship between child and father?

More men than women raised their fear about this (7, 17% and 5, 6% respectively).

The act of telling the child was often seen in some way to be a potential threat to the relationship between father and child.

"Anxiety about the non-biological father rejecting the baby was high around the birth and during the stressful weeks of new parenthood when a mother is not at her most rational. This may be the same for a normally conceived child." (Mother of an eleven-year-old)

"We hit a crisis point about telling our son. My husband was not happy with this. He was frightened of the outcome and needed reassurance from a professional. It was totally unknown territory." (Mother of a fifteen-year-old)

"My son was very upset at first because he thought I was his dad and couldn't understand but he's all right now. But I was very upset I thought I had lost him forever and things would never be the same again, but if anything we are closer than ever and I love him very much" (father of a nine year old)

"A concern about how they will react when it sinks in. I am not their biological father, probably groundless fears however it does concern me, especially when they move towards being teenagers" (father to a seven and four year old)

Practising my 'script'

Some couples discussed how they were considering how they would tell their child, women commented 3 (4%) times, and men 2 (6%) times. This was often seen as a way to practise what would be a difficult task. Some felt it was helpful to start when the child was young, still a baby.

"Our son is 17months old. I have talked to him about it pretty much since he was born, to practice my script!" (Mother of a seventeen-month-old baby)

"I have based it on the 'My Story' book. I occasionally tell the baby now almost as a practice run." (Father of a three year old and a baby under one)

Knowing the right time to tell.

Many couples expressed some anxiety about knowing the right time to tell their child. Women commented on this more than men did (14, 17% whilst men commented only 3, 8% times). Many referred to the 'My Story' book and using this when the child is aged approximately 4 years of age. However it was often felt to be an isolating and difficult task. In particular one which was easy to delay, or postpone.

"It was very hard at the time but I certainly felt that it would be much more difficult if we had left it as there is a great temptation to." (Mother of a fifteen-year-old, told at aged nine)

"I'm not entirely sure what to say and how to go about it yet, still hoping to learn from others, DI network, frightened that when we begin to tell them, that it all goes well." (Mother of a two-year-old)

The success of DI.

The overwhelming response from couples participating in the research was of gratitude and relief that they had succeeded in DI, (women commented 11, 14% and men, 7, 17%). Many explained how having had a child had changed their lives, and

none expressed any regrets. However there was a sense that the pain of fertility difficulties was still present, though definitely eased by having had children.

“99% of the time the fact that the children were conceived through DI is not in my conscious level of living my life, I simply forget that they were conceived in an unusual way as it now does not seem that important.” (Father of a four and one year old)

“If I could go back in time and be told that an attempt with husbands sperm would work I would not change a thing, I love the boys I've got to bits.” (Mother of 3-year-old twins and a baby less than one year)

“We consider ourselves greatly blessed for our family and the past and treatment is fading daily from our minds. Never will forget our desperate longing for our family and how wonderful the delivery of our boys into the world was. Our lives have been enriched through this experience and I have enormous compassion understanding now for others in similar straits.” (Mother of twins, two years of age).

CHAPTER FOUR

DISCUSSION

“Going for DI was the first positive thing we were able to do after the years of sadness, anguish and frustrations caused by infertility. After we grieved for the child we would never have, it was our first opportunity to look forward.” (Man, who now has a child after DI)

This descriptive study explored the experience and concerns of couples undergoing DI treatment and those who have had a child through the use of donor insemination. The design of the study was influenced by the response rate from the two samples, as the low response rate from the clinic sample limited the sample size. The difficulties in recruiting participants and the taboo and secrecy of DI are discussed in more depth in this section. This study explored the attitudes of couples towards openness and secrecy and their intentions regarding telling the child or not of their origins. Qualitative data provided some insight into how couples consider, and begin to tell their DI child and what were felt to be the most difficult aspects of DI treatment. The main findings of this study are described below; these results are then considered in relation to the literature. The limitations of this study, further clinical and research implications resulting from this study are also discussed.

4.1 FINDINGS

The main findings fall into four areas:

A. Distress and Mood levels of participants

The main gender difference for those having treatment was that women were significantly more distressed about the fertility difficulties than the men. Both men

and women obtained relatively high scores on the HADS anxiety scale, falling in the borderline range. They also obtained scores in the high range of the Fertility Adjustment Scale (FAS) suggesting that DI treatment is experienced as challenging.

There were also gender differences identified in the group of participants who now have a DI child. Women were found to be significantly more anxious than men and fell in the borderline range, whereas men did not. Women were also more distressed about fertility difficulties than men. In both phases (in treatment and after) women rated their partners' distress as higher than their partners were rating themselves. This may suggest that men are actually more distressed than they rate themselves. Another possibility is that there is a mismatch between women's perceptions of their partners' distress and how the men are rating themselves, or that women are particularly concerned about their partners feelings when undergoing DI treatment.

B. Concerns and the most difficult aspects of DI

The concerns of those in treatment revealed that the main pre-occupation was about becoming pregnant, then about the donor as well as about telling the child. There was a significant gender difference in that women rated more highly the concern of 'getting pregnant' than the men. It is interesting that even before a pregnancy has been achieved both men and women were quite concerned regarding the issue of telling the child.

In the group of men and women who have had a child and had completed treatment it became clear that concerns changed over time. Women and men were similarly

concerned about telling their child and about the characteristics of the donor. Women were found to be significantly more concerned than men regarding their child's right to information at aged 18. Findings reveal that after the birth of the child/children, the future implications for the child become the main concern. Women were more concerned about 'how' to tell the child. One possibility is that this is because women mainly bear the responsibility for telling their child.

For those couples undergoing treatment there were several aspects of DI that were reported to be particularly difficult. Couples who had completed treatment expressed many of the same concerns as those who were undergoing treatment. These were as follows:

Length into treatment and continual failure.

Both men and women in treatment and afterwards discussed the difficulties of ongoing and lengthy treatment. This was felt to be very distressing, and those in treatment raised the fear that they would remain childless. Those who have now finished treatment referred to the 'emotional roller-coaster' of monthly treatments.

Impersonal treatment

Both groups made reference to incidents of insensitivity on the part of clinic staff, and that their feelings were not acknowledged during treatment.

Relationship issues

The men in the treatment group in particular, were concerned about their relationship, describing concerns about the negative impact that the DI treatment had on their relationship with their partner. Men and women both described the

importance of having a strong relationship and utilising support from each other throughout the treatment.

Male infertility issues

Many men in the treatment and after treatment group discussed the difficulties they had faced when coming to terms with the diagnosis of infertility. They discussed their feelings about the way in which male fertility problems were handled in the health service, and acknowledged the difficulties presented by DI as their infertility had not been 'treated'. Women also spoke, to a lesser extent of their feelings about their partner's fertility difficulties, and the impact the diagnosis had on their partner.

The Emotional impact of DI

A considerable number of women undergoing treatment spoke about the emotional effect of having DI. This involved feelings of depression, grief and anticipation every month after the insemination. Very few men in either group commented on this.

The insemination

The insemination was an aspect of the treatment often found to be difficult, although more people commented on it retrospectively. Despite it being a technically simple procedure both women and men commented on the emotional impact of the insemination. Men spoke of feeling uncomfortable and helpless, whilst women recalled the difficulty coming to terms with the use of another man's sperm, of carrying 'someone else's child' and of the invasiveness of the procedure.

C. Counselling and information needs

There were very few requests for counselling from the group undergoing treatment. Couples in both groups did not express interest in further discussion with their doctor, but the majority (61, 73%) of those who had completed treatment felt they needed further information about DI. Information that they felt they needed tended to focus on the future implications for children, long term issues and anxieties about the relationship between father and child. Several couples expressed a wish for more openness and open discussion during treatment.

Those in treatment did not want further discussion with the doctor, but expressed a wish for more support by meeting with other couples, having advice during treatment, and the need for counselling in the early stages of DI, before treatment begins.

In terms of the implications counselling it was found that whilst issues about medical procedures and the donor were covered in sessions, issues about telling others, telling the child and how to tell the child were rarely discussed. Nearly half (41%) of those who were no longer in treatment stated they had not been given the opportunity to discuss their feelings when in treatment.

D. Telling and secrecy

There were significant differences between the two treatment groups in terms of intention to tell a potential DI child. The majority of those from the clinic were undecided or felt they would not tell whilst all those from the DI Network planned to tell. This research suggests that factors that are influential in terms of intending to tell the child are educational status and having spent more time coming to terms with

infertility and the need for treatment before embarking on DI. The most significant difference was that the couples who belong to DI Network had actively sought out further support and information, addressing long term concerns about DI treatment and having a child. This perhaps makes it easier to make the decision to tell the child or not, as one has access to current knowledge regarding the pros and cons of telling. Through contact with the DI Network, couples meet with other couples and learn of the book 'My Story', thus they are provided with some 'script' with which to tell, unlike those couples from the clinic who do not seek such support.

Those who were undecided, or wished not to tell their child were also found to be more distressed about their fertility difficulties. The direction of this relationship is unclear. One explanation is that this group had difficulties coming to terms with the need for DI, and continued to feel very distressed about the fertility difficulties. These unresolved feelings about their fertility problems might make it difficult to process thoughts and feelings about the specific aspects of DI such as the donor characteristics and telling the child. This may particularly be the case when the decision regarding telling is related to a 'future' situation, which at the treatment stage is by no means guaranteed. Findings on the main concerns of couples show that, at this stage the main preoccupation is with becoming pregnant.

Another consideration is that the group who are undecided or plan not to tell often referred to the need for more information and advice on this area. Thus, the lack of support available for these couples may increase the level of distress about fertility difficulties and the DI treatment.

One major finding relating to telling and secrecy was the educational difference between the group who plan to tell and those who do not or who are undecided. Those who plan to tell their child come from a more highly qualified group than those who do not plan to tell, the majority of whom left school at 16 years of age. Whilst the meanings of this are discussed later, one explanation is that the couples who are undecided have not been given the access to materials that might help them consider the long term implications of successful treatment, unlike the more qualified DI Network population.

For those who already have a DI child, many factors were raised in their accounts of telling their child. It was felt important to make the DI origins seem a natural part of the relationship with the child. Couples described their account of telling, making it personal for the child, including photos, and emphasising how 'special' the child is without making them feel 'different'. The need for a 'script' and the use of the 'My Story' book was often referred to. From the accounts that couples gave, the decision to tell your DI child was not easy, and the incident of telling is sometimes difficult and painful. However, no one regretted having told, and those who had not yet done so, spoke of their fears and anticipation of how their child/ren would respond.

There was a wide range in the age of the child when told. However, it seemed that those who tell their child at an earlier age found it somewhat easier. Most seemed to plan to tell their child at age 4 or 5 with the aid of books such as 'My Story'. Some couples stated there was a temptation not to tell, as the child was young, and the news might be upsetting in some way. Others emphasised that if the child is told at

an early age it should feel as if it is something they have always 'known'. No one reported any difficulties about the father-child relationship, although several raised their fears about it during earlier stages of treatment. This is perhaps an issue which couples need further help and exploration in, at the early stages of DI treatment.

4.2 FINDINGS IN THE CONTEXT OF LITERATURE

Distress and mood

In terms of the distress and mood levels of couples participating in this research the findings support earlier work by Cook et al (1989) who found that both women and men experience high levels of anxiety but not depression.

Woollett (1991) draws attention to how in our present society infertility is generally seen to have more impact on women's lives and sense of identity than men's. She points out that it is generally assumed that women are more likely to be infertile, thus when men need to be investigated it may come as a surprise and with shock to the male partner. Even when there are male factor difficulties, such as for those seeking DI, it is still the women who are expected to bear the brunt of treatment. This is seen in the treatment group where women experience the treatment as interfering more with daily life and are more distressed than the men.

Women's ratings of the interference of DI is due perhaps to the obvious disruptions caused by arranging appointments around their menstrual cycle, having the inseminations, and perhaps taking drugs to stimulate ovulation. There is also a psychological interference that may at times go unnoticed. Both men and women wrote of feeling that DI dominated their minds, making it difficult to function properly at their 'normal' level. In particular, for women there is also the added

responsibility of trying to achieve a pregnancy, becoming focused on their body and the wait after the insemination, hoping that menstruation does not occur.

The results of this study do not support those of Blaser et al (1988) who found that DI did not pose a threat to men, and that infertile men were not a psychological risk group. This research suggests that men experience high levels of anxiety and distress about their infertility throughout treatment. There are also pressing personal issues for them about the need to have DI and coming to terms with their own infertility.

The personal significance of one's fertility difficulties also seem to continue after the child is born, as many men acknowledged that DI does not remove the fertility difficulty, and wanting more information on their diagnosis.

Another factor in examining the distress of men undergoing DI is that women rate their male partners as more distressed than men rate themselves. One explanation for this is that women are particularly concerned about their partner's reactions, given the sensitive nature of DI and the rarely expressed feelings associated with DI. These feelings may invoke guilt about 'being unfaithful' or of a man's feelings of inadequacy regarding his infertility. This is a dynamic discussed by Raphael-Leff (1991) where in active interventions such as DI, sexuality and procreation become separated as the couple accepts a 'strangers' interference in their 'intimacy'. Goodman and Rothman (1984) also found that women undergoing DI had difficulties discussing these fantasies about the donor, or feelings of 'shame'.

Another explanation for this discrepancy in rating of distress is the low involvement that men reported having in the treatment and their high levels of concern about the effect of DI on their relationship with their female partner. These difficulties in relationships might perhaps influence the ability of men to adjust to their fertility difficulties, perhaps expressing more concern about their female partner's grief and distress than their own. This research also perhaps supports the theory that infertility is experienced as a life crisis (Clamar 1980), where the infertile partner (the man in this case) feels guilt and anxiety about his infertility. This has implications for services in terms of offering counselling for men and women with the opportunity to discuss some of these feelings together.

These gender differences relate to work by Monach (1993) where men and women were found to have very different experiences of fertility treatment. He found that at the outset of treatment men and women expressed similar feelings. However, over time the men were less likely to admit to feelings of distress, whilst women were more likely to identify such reactions. This can be seen in this study to some extent where women continue to report themselves as distressed. In Monach's (1993) study, women reported feelings of guilt, distress, bitterness and feeling unable to fulfil the role of mother. Men in his study linked their infertility with virility, rather than an inability to be a 'father'. This is also reflected in comments made by men and women in this study.

Men and women who were undergoing treatment also fell into the borderline range for anxiety (HADS). One suggestion to explain this is that the process of undergoing

treatment, discovering infertility difficulties and coping with the DI element is understandably distressing and anxiety provoking. Thus, these anxiety levels can be seen as a reaction to the treatment, the monthly 'ups and downs', anxiety about the donor, and feelings about the fertility difficulties. Much of this is reflected in couple's accounts of the most difficult aspect of treatment, which is concerned with both general infertility issues and the DI itself. For example, the lack of control and the continual failure are issues often referred to in all fertility treatments whilst the donor issues and the insemination are those pertinent only to DI. Brand (1987) suggests another explanation that calls for a thorough evaluation of couples who decide to use DI. The anxiety and distress levels of the couples in treatment suggest that they are perhaps a vulnerable group. The donor semen in this case can be seen as an external factor that is introduced into a 'complex dyadic system that is particularly susceptible to emotional stress'. (Brand, 1987 p.104).

Both men and women in treatment scored 1 SD (mean scores of 49) above the mean of the norms for the FAS, suggesting that they may be having difficulties adjusting to their fertility difficulties (Glover, Hunter & Richards. In press). Raphael-Leff (1991) suggests that the lack of clear boundaries in infertility treatment, and not knowing when to accept failure, are linked to adjustment to infertility. This can be seen in the description by one of the participants who stated "you become addicted to it, just one more cycle". This difficulty adjusting to fertility difficulties can also be linked to the lack of control couples' felt they had over the process of DI and treatment. This might be particularly difficult for 'male partners' in DI, as the 'treatment' does not deal directly with their problem. Research by Crowe (In Scutt, 1990) discussed the

difficulties that women who undertake IVF treatment experience in adhering to boundaries and the time limits they set themselves in treatment. She found that many women attempted all avenues in order to have a child, and that media reports of 'successful' treatments exacerbated the need to 'keep trying' and not to accept 'failure'.

Stanton and Dunkel-Scheller (1990) suggest that in order for healthy adjustment to infertility couples must work through their feelings and mourn the loss of their potential child. This is perhaps seen more in the DI Network population who described time spent coming to terms with infertility before embarking on DI. This finding is supported by Berger (1980) who suggested the importance of having some delay before treatment, and of not being 'rushed in'. In contrast, couples from the clinic waited prior to treatment for reasons more out of their control, ie, not intentionally, such as waiting lists and investigations.

Moos and Schaefer (1986, in Stanton & Dunkel-Scheller, 1990) pointed to the adaptive tasks that couples commonly go through in infertility and the importance of addressing its meaning and personal significance. Findings in the present study suggest that as distress reaches levels of clinical significance, self-esteem and role functioning do suffer. This is seen in the concerns of men and women in treatment, who expressed anxieties about self, relationships, fear of the future, and difficulties functioning both at work and socially.

In this study, women's ratings of their distress about fertility difficulties were higher than that of their partners. This was also true for women after treatment, when they had a child. An explanation given by Monach (1993) is that women feel the need to protect their partner from any outside awareness of infertility. This is no doubt

exacerbated in DI treatment, which has a history characterised by taboo, controversy and stigma. Lakser and Borg (1989, in Daniels, 1993) also suggest that men are more likely to keep DI a secret, and that secrecy in DI is bound up with protection of the infertile male.

The higher levels of distress expressed by women also support findings by Beureparire et al (1994) who found that women who had received repeated treatment cycles were more at risk of developing clinical significant symptoms. This study found that couples in treatment had received on average 6-7 cycles, and most anticipated many more. This finding indicates the need for supportive psychological interventions at different stages during treatment, for example at diagnosis, and later after a number of failed treatment cycles. Raphael-Leff (1991) considers in depth the psychological impact of the diagnosis of infertility on couples. Here, the emotional trauma of the infertility diagnosis has repercussions on all levels; intrapsychic, interpersonal, psychosexual and occupational (Raphael-Leff, 1980).

Men in this study emphasised their concern about the impact of DI on their relationship with their partner. Humphrey and Humphrey (1987) suggest that men require emotional support from their partner in order to adjust to their infertility. Woollett (1991) points out that the negative impact of infertility on a couple's relationship is greater when the 'cause' is male infertility. Earlier research has raised the possibility that men cope less well with the knowledge of their infertility and are less used to discussing their feelings and seeking help (Connolly et al 1987, in Woollett 1991). Findings from this study suggest that men are greatly concerned

about their relationships with their partners, and draw great strength in coping with DI treatment by utilising support from their partner or from agencies such as DI Network meetings. Men were also concerned about their infertility and many felt the need to address and explore this, often, as it had not been by doctors or the clinic. It may also be that men in this situation need support, yet in accepting this it may feel to threaten their tradition 'male role, i.e. in supporting their partners. Hence the men in this study expressing their feelings of being 'out of control', and helpless in the insemination which exacerbates feelings of guilt and anxiety.

This study found that in many ways, men do become rather marginalised by DI treatment. The importance of involving male partners in treatment (Lasker & Borg 1987) and particularly in acknowledging their feelings prior to or during the insemination should not be underestimated.

Findings from this study illustrate that whilst men and women share similar concerns, they differ in significant respects. This is an issue highlighted in work by Koval and Scutt (In Scutt, 1991) who point to the dangers of only emphasising the 'couples' needs as if men and women are involved equally in the stresses of treatment. As Monach (1993. In Snowden & Snowden, 1997) found, women's concerns focused on their emotional pain whilst men discussed to a greater extent their partner's distress, their own diagnosis and the process of the investigation. These conclusions are similar to findings in this study where women expressed concern over the emotional impact of DI, whilst men expressed feelings about their diagnosis, seeing their wife in distress and the impact of DI on their relationship.

Rowland (1985, in Scutt, 1991) also warns of the danger in assuming that if the couple reach the 'end result' (the baby) that they forget the pain and distress their fertility difficulties caused them. The importance of acknowledging the feelings that men and women may have when faced with the decision of using DI are issues that may need resolving, despite being offered ways to have a child:

"Their sadness and hurt fade with time, but are still there, and can resurface. Infertile people have to accept that they can care for and 'parent' a child or that they can be creative in other ways, and that takes time". (Rowland. In Scutt, 1991 p91)

The changing concerns of men and women

As one might expect, the concerns of couples shift and change after having a child. As put so clearly by one participant who stated that after having a child, the problems are just beginning, such as disclosure and dealing with others reactions to DI. This is in accordance with Seigal (1993) who suggested that the concerns of couples change during the process of adoption, where the first goal is to find a child. Later on, issues about sharing the information with the child and fears about relationship difficulties become more prominent. However, it is interesting that even whilst undergoing treatment men and women rate quite highly their concern about telling the child, which suggests that this is an issue that needs to be raised with the couple throughout treatment. If the issue of telling or not is addressed in the early stages, couples might feel in a better position to make their decision and to think through the consequences. For the majority of the clinic group who were uncertain, or who planned not to tell, there is arguably a need for further advice and information for these couples in order to make options available to them. The men and women who were undecided were

found to be more distressed about their fertility difficulties. One explanation is that they had not taken adequate time before pursuing DI treatment and their situation is exacerbated by feeling the need to keep the DI treatment secret, i.e. they may be less likely to talk through their feelings about infertility with significant others.

For those couples in treatment, women rate their concern regarding 'getting pregnant' significantly higher than the men rate. The concerns of those who then have a child are seen to shift to concern about telling the child and child's access to information on the donor at age 18. Women were also quite worried about donor issues, such as the characteristics of the donor. They were more concerned than the men about a child's access to information, perhaps as men were uncertain about what information they wished to have on the donor.

The child's future and the implications for them regarding DI were the main concerns expressed by couples who had a DI child. Women expressed more concern than men did about how they might tell the child. Although no data was gathered directly on this issue, responses to open questions suggest that it is often women who first tell the child, men reporting that they "follow (their) partners lead". Couples also expressed a concern for the future in terms of wanting another child, so anticipating the painful process of DI again.

More men and women described their feelings regarding the actual insemination when asked retrospectively. This is perhaps an issue not focused on when currently undergoing treatment as it is an aspect that has to be carried through, and the focus is on achieving a pregnancy. However afterwards (when they have a child and are no

longer in treatment), many of the men and women described in depth their experience of the insemination, and the potential psychological impact of it. Women described the insemination in terms of fears about 'infidelity' and the experience being 'cold and clinical'. Men also referred to the donor aspect of the insemination, seeing another man's sperm, and fantasies about who the donor was, one man referred to the insemination being 'loveless' and the distress caused by being present at the insemination. Raphael-Leff (1991) focuses on the unconscious fantasies that often accompany the specialists in fertility treatment. The couple may experience a whole host of feelings such as excitement, anticipation and anxiety as they embark on treatment, bracing themselves for 'rejection' at each cycle and feeling both gratitude and resentment towards the doctors. They may also experience anger at their dependence on a service that they would be devastated to lose. Issues of power and control within the treatment are also related to the psychological impact of the insemination. Raphael-Leff (1991) draws attention to the trust that the couples invest in the 'magical omnipotent' specialist. These feelings are then furthered by medical 'mystification' and the language used in treatment which arouses emotional connotations such as 'incompatible mucus' and 'hostile cervical secretions'. Participants in this study make reference to this in their accounts of the "God-like" doctors and the lack of control over treatment. Some couples expressed their ambivalence towards the clinicians in terms of both gratitude and anger.

When there has been a history for some women of difficulties conceiving, there may also be a lasting impact on their reactions and their experiences of pregnancy and motherhood (Woollett, 1991). She found that women often feared that the pregnancy

might go wrong, and also that having had fertility treatments can influence attitudes towards parenting. Whilst in general, the findings in this study reflect the enthusiasm and joy with which couples embrace parenthood, they did acknowledge that at times they felt 'overprotective', and needing to feel 'eternally grateful' for having a child.

The actual treatment itself may evoke powerful and distressing feelings in the couple, and although Raphael-Leff (1991) draws particularly on IVF treatment, much of her work is helpful in considering DI. She states that the couple may have an irrational fear that there is only a 'limited numbers of babies to go round', and with only 3 attempts at IVF allowed they may feel them to be "three wishes", which are both finite and awe-inspiring. This is seen in this study where couples in this study expressed their fears about the limited number of treatment cycles they had left, and of time 'running out'.

Couples in treatment and those recalling past treatment expressed difficulties concerning the length in treatment, and also the 'two-week' wait following an insemination. This is an issue also explored by Raphael-Leff (1991) who divides time into 3 dimensions; 'calendar' time as the couples observe other children growing up, 'periodicity' with one's biological clock and menstrual cycles, and finally 'posterity' with the yearning to be able to continue the genetic immortality one had hoped for. This last dimension relates to the concept of 'genetic death' and adjustment to the knowledge that the man cannot have a blood related child. The man's feelings of marginalisation in treatment (which was found in this study) and the awareness that DI only finds a way around the problem, but does not solve it is something that may hinder adjustment to his infertility.

Couples in this study expressed the disparity between the clinical, emotional and psychological aspects of treatment. Whilst information was given regarding the medical aspects and the process of selecting and matching donors, it is clear that in many cases the emotional impact of undergoing the treatments was not discussed. Many couples in this study expressed their concerns and feelings about the donor, partner, and any future child. However, these areas were less likely to have been discussed during implications counselling sessions.

In terms of examining concerns regarding the future and decisions about telling a potential child, Grotevant (1997) discusses the development of identity in adopted adolescents. The coherence of identity narratives is emphasised and serves as a useful window on adolescent development in DI. Couples who had a child and who were planning to tell raised their fears of how the child would deal with this knowledge in their teenage years. Grotevant (1997) found that variations in open or closed adoption practices moderated the relation between family processes and adolescent outcomes. Open adoption practices and talking with ones child about their origins was found to be important for the child's future identity development. Thus, for those couples who help their child develop a coherent story regarding their origins from DI at an early stage, this perhaps helps their future development as adolescents.

Counselling Needs

Some couples expressed their concern that they were being 'assessed' for suitability for DI treatment when they met with the counsellor. These findings about

counselling during treatment illustrate the dilemma between providing an open and confidential environment and one in which couples can talk openly about their fears and anxieties concerning DI. Very few couples expressed a need for counselling, and some spoke of a fear of being judged or excluded from treatment. For couples who hope to become pregnant there is perhaps a need to try to maximise all possibilities of being accepted for treatment and present as 'perfect potential parents'; avoiding a discussion about 'negative' or ambivalent feelings. This also perhaps linked to the difficulties for couples who felt the power imbalance between themselves and the consultants and the need to be 'grateful' for treatment.

It is important to bear in mind that the DI Network group who had a child were an earlier cohort, and that counselling within the DI clinic setting is now more widely available. However, from this research it is evident that clinics vary widely in their approach both to secrecy, telling and dealing with the psychological impact of DI. Couples who have older children commented in this study on the importance of the change in the DI climate, and the need for increased openness:

"The subject was taboo in 1987 we were told not to tell, the deceit was terrible we told close family and a few close friends but we were always worried they would tell, but needed to talk to someone." (Man)

"The clinic we used told us that this treatment must be an absolute secret from everyone. This increased the stress of an already very difficult time over a period of time after having our first child... The clinic refused to discuss it with me and my GP had no answers. Openness must be encouraged children have a right to know of their DI conception and secrecy had no place in a healthy family relationships." (Woman)

Research by Crowe (In Scutt, 1991) highlighted women's awareness of the power imbalance between patient and doctor when undergoing fertility treatments. Women

experienced an implicit pressure to present a rational attitude to treatment and failure. Counsellors were also rarely requested, as women felt that if they were expressing negative attitudes or feelings it would jeopardise their treatment. This may also relate to the low interest in counselling in this study, with more couples retrospectively wishing they had seen counsellors.

Crowe (In Scutt, 1991) also found that women expected only a 'perfunctory' role from their doctors; this can also be seen in our findings where couples did not wish for further discussion with their doctors.

Perhaps the importance of counselling during the DI treatment process is in terms of helping the couple to see DI 'from the child's point of view. Thus, rather than the focus being on the 'baby' it is essential to think of the DI child that grows up to become an adult, this is emphasised by Snowden and Snowden (1997) who state:

"Whilst it may not appear important for a baby to know about it's biological origins, the interest of a young adult in such knowledge is another matter." (Snowden & Snowden, 1997, p18)

Discussion of this type in treatment settings might facilitate more sensitive discussions for couples who are undecided about telling.

Secrecy and Openness

From these descriptions it is clear that the secrecy and stigma of DI can place a great strain on both the couple and on individual coping mechanisms. For those who reported telling others, although the majority reacted positively, some negative reactions were reported. This suggests that even after having decided to talk with others about DI, telling is not necessarily an easy option.

Rowland (1985) discusses the assumption that secrecy is of paramount importance in DI in order to protect the three parties involved. She calls for further information needed on the intentions and opinions of couples undergoing DI and of donors. Daniels (1989) has examined the issue of telling the child and the donor's motives in some depth, and found that almost all donors were interested in knowing the outcome of their donation. Seventy-three percent were still prepared to donate should it be possible for children once aged 18 to trace their identity. In terms of fears as to donor's motives Daniels (1989) found that altruism, (the wish to help infertile couples) was the main motivating factor. His findings contradict commonly held views by the public and consultants that donors are motivated by money and would not donate if there was a risk that the child could trace them. Daniels (1989) calls for a psychosocial approach to the donors' position in the dynamics of the relationship between the couple, the consultant and the potential child.

Blyth (1991) has also drawn attention to the dilemma of openness in DI, where there has been only scarce research in this area. Whilst there are now calls in HFEA guidelines for greater openness, this is often balanced against clinicians fears about a shortage of donors. More recent work by Daniels (1996) equates the donation of semen with blood, emphasising the need to increase the numbers of men who might donate, thus allowing DI to gain greater social acceptance in society. Clinics and their policies have a vital role to play in this, needing perhaps to promote donors as men who "donate rather than sell their semen" (Daniels, 1996, p751).

Findings from this study suggest that possible influences on the decision to tell the child or not, are educational status and having access to more information and support from other couples. Those who plan to tell their child had also spent a longer between diagnosis and seeking DI treatment, allowing time to come to terms with their infertility. In contrast, those who were not DI Network members, and the majority of whom planned not to tell their child perhaps felt somewhat more isolated and alone with the dilemmas of telling or not. It is also important to bear in mind that other research (Golombok et al, 1995 and McWhinnie, 1995) found that the majority of couples choose not to tell. As the group who were undecided about telling did not belong to a support group, they perhaps lack information on how to tell, possibly then making the decision on the grounds that it is best not to disturb the status quo and thus maintain secrecy.

However, many of those who are undecided or plan not to tell, have spoken to at least one other person about DI, and have the added difficulty that the child may find out accidentally. Research has shown that in circumstances where this information is revealed to the child inadvertently, such as in cases of marital breakdown or during a family argument, the consequences are likely to be worse for the child than if they grow up in the knowledge of the information (Clamar 1984, McWhinnie, 1996, in Snowden and Snowden, 1997).

Many couples from the clinic felt they needed further information in order to decide about telling the child, as there was a fear that telling might disrupt the child's happiness. For those couples who made the decision to join a group such as the DI Network they have had access to this information and appear to be better informed.

Findings from this study suggest it is likely that when people are undecided about telling and concerned about the maintenance of secrecy, there is an association with higher levels of distress about their fertility difficulties. The group of men and women who are undecided or plan not to tell any potential child were still concerned about the issue of telling the child and their families, no doubt exacerbating any anxiety and distress regarding their treatment. This suggests that those who are undecided or who had decided not to tell were more preoccupied with fertility issues, and therefore not able to have the resources to process decisions about telling the child. It may be advantageous therefore to take time to grieve fertility difficulties before beginning DI treatment.

Woollett (1991) drew attention to the possibility that whilst secrecy helps couples to think of their child's conception as 'normal', this also ensures that male infertility remains a taboo issue, and that DI is seen as something to be ashamed of. This is seen in this study where men who plan to tell their child express their feelings of not being ashamed of their 'fertility difficulties'.

Women undergoing DI treatment who participated in this study were very concerned about the level of secrecy and stigma surrounding DI. This might mean that for women social support might be more difficult to obtain, and they may not have been able to utilise their usual coping mechanisms. The taboo about infertility and DI might also hamper women's typical way of dealing with stress, ie by accessing social support. A study by Woods, Olshansky and Draye (1991. In Hunter, 1994) found that women with fertility difficulties found sharing their experiences with a

supportive partner, or close female friends to be helpful in coping with treatment. Other useful strategies were in looking at one's situation from another perspective, investing in other areas of life such as work, or seeking advice about applying for adoption. One can see that with the stigma of DI and the ongoing cycles of treatment how some of these resources become hindered. This is seen in a quote from one of the participants:

"It became obvious to me that secrecy was harmful to everyone, but I didn't know who to go to for help and advice" (woman who now has a child)

This finding supports earlier work by Monach (1993 in Emmy Jennings, 1995) who found that men were less likely to confide in any group within their social network.

He related this to the greater social acceptability of women expressing their feelings and women's internalised role-model of how they should be coping.

Gender differences in coping strategies may also relate to their different levels of distress.

There is tentative evidence in this study of a relationship between level of education and telling the child or not, however this clearly requires further research. Level of education was not related to other factors such as distress or mood, but was only related to telling. One explanation is that the DI Network sample, who have higher educational status, are more attracted to organisations such as the DI Network, and perhaps more likely to seek out advice. This is compared to those that are not members and are reliant solely on the clinic for advice and information.

An alternative explanation is that there is a clinic bias where clinics, unconsciously orient the more educated couples towards more information, and explore other

options in terms of telling or not. To balance this, those couples who are more educated and work as professionals may be more comfortable about confronting the clinicians at the clinic, and researching the issues they feel to be pertinent to having a DI child. It may also be that those couples with a lower educational status but who plan to tell, seek support in other ways, perhaps avoiding the DI Network.

4.3 THE LIMITATIONS OF THIS STUDY

There were a number of methodological difficulties with this study, which are discussed below, with a view to improving and developing research in this area.

The two groups of participants in this study were drawn from different samples and while they did not differ in terms of most demographic variables or distress measures they differed in terms of educational qualification, the DI Network group was more qualified than the hospital clinic group. They may also differ in other respects uncontrolled for in this study. As the groups were significantly different in terms of educational qualification, if repeated, this should be controlled for. However, in trying to access the hospital clinic sample, due to HFEA guidelines it was difficult for the researchers to gain access directly to the participants. There was a low response rate from the clinic (36% opted in) and it may have been that some couples had anxieties in completing the 'opt-in' form due to a fear that clinic staff might access their questionnaires. Reports from several women to staff at the clinic suggests that they found it difficult to complete the questionnaire due to not wanting to tell someone outside the family about their DI treatments and the issue of telling the child or not. Staff at the clinic confirmed this stating that the majority of couples attending for treatment wish to keep it secret.

This is a problem inherent in research into DI where there are difficulties accessing clinical populations undertaking DI as the majority plan not to tell their child. It is perhaps likely that having to write down and describe the experience of DI is a barrier to those who have not spoken to anyone about their DI to participation in research such as this. Thus where secrecy in DI perhaps equals non-participation in research, this presents a dilemma for researchers, who may have to seek other ways to recruit a representative DI sample. Lee (in Emmy Jennings, 1995) estimates that approximately 90% of couples wish to keep the DI a secret, perhaps only sharing it with close family. One might expect that those couples who have told no one and plan never to tell the child would not perhaps wish to take part in such a study. Thus, it may be that those who did respond and participate in this study are those who are slightly more undecided about telling and more comfortable in talking about their DI treatment.

It is important to consider the methodology of this research, and although it provided some insight into the quantitative ratings of men and women in areas such as distress, mood and concerns, it is clear that this field would also lend itself to qualitative research. One area for future research, given the two very different settings used in this study is to examine in greater depth the discourses used in various clinics, in terms of secrecy and long-term issues of telling. This might be done using interviews with staff and clients, applying discourse analysis to examine language. This would support previous work by Daniels (1996) which suggests that clinics and their different approaches to secrecy have a vital role to play in increasing openness in this field. However, the issue of confidentiality and secrecy in DI obviously plays

a part in preventing participants from coming forward, which is why the DI Network were approached since they could provide some insight into couples who believe in greater openness. It was difficult to find couples who could be compared on the basis of telling versus secrecy, which would have been a preferred approach.

This study explored the views of predominantly 'white' couples undergoing or having completed treatment. Whilst 'non-white' couples perhaps face greater cultural stigma regarding fertility treatments and DI, the bias towards 'white' couples possibly also reflects the difficulties in providing DI for different ethnic groups, in terms of a shortage of donor sperm. It also selected only heterosexual couples, and there is no doubt that there is also a need to research other groups who use DI. For example, the DI Network also has as its members a number of single women or lesbian couples who use DI. Although one might anticipate that there might be similarities between these groups in terms of levels of distress and concerns, these groups may also face other difficulties, such as isolation, or the stigma and reaction of others towards them and their child. One has only to cast one's mind back to the beginning of this study to recall the hostility in the news debate aimed at women who decide to have a child through DI without being in a relationship with a man. Although this study has to a certain degree focused on the difficulties faced by men and coming to terms with their infertility, for those families who are viewed in society as 'atypical' equally painful dilemmas have to be confronted. As most countries have no law about who can or cannot have DI (Sweden currently only allows DI between married or cohabiting heterosexual couples), each clinic is left to make its own decision. Thus decisions about suitability for treatment are varied but

also reflect social stereotypes about parenthood. DiLapi (1989) discusses the motherhood hierarchy, which consists of women who are defined as most, marginally or least appropriate to bear and raise children. Lesbian and single women who thus seek DI are perhaps viewed within this conceptual framework when approaching clinics for treatment. However, Downie (1988) draws attention to the hurdles the lesbian or single woman will have had to go through in order to have a child through DI, arguing that the child may be much wanted, perhaps making the woman a 'better mother'.

Another group who have not been studied consequently are those couples who have difficulty coming to terms with their infertility and those who do not conceive. This is an area rarely explored, perhaps as it is difficult to access those couples who give up treatment, so little is known about their adjustment to their fertility status or their reactions to DI treatment (Edelmann & Connolly 1986 in Woollett 1991). This is an essential aspect of DI that needs further study, bearing in mind that the success rates of DI are only 8.7% (HFEA, 1995) and the length of time couples undergo treatment, as well as findings from this research of the psychological impact of repeated unsuccessful cycles.

4.4 IMPLICATIONS OF THIS STUDY

From this study it is clear that further research into the complex area of whether, when or how to tell a DI child is called for. This would be in accordance with current HFEA guidelines which suggest that couples undergoing treatment be given help and support in thinking about the implications for the child in relation to telling

or not. This study provides some tentative evidence that the issues around telling and secrecy are far reaching, and that 'total secrecy' is difficult to maintain. Men and women expressed concern about telling and secrecy at all stages of treatment, during treatment, and afterwards. In addition, some women spoke of the fears that they had had during the pregnancy.

For men it is also clear that there are personal concerns about coming to terms with fertility difficulties, men may need support and counselling when they are considering and undergoing treatment with their female partners. Other research suggests that greater male involvement and information giving is beneficial (Lasker & Borg, 1989).

One recommendation here is the provision of individual and then possibly, group work for men and women undergoing DI treatment. A study by Goodman and Rothman (1984) found a group setting beneficial for women in terms of sustaining involvement in treatment and preventing possibly damaging psychological effects of their infertility. It also provided the opportunity to address the 'omnipotence', which was assigned to the doctor in the transference to the group leader. In particular they identified a theme that arose in the group in terms of the 'fear' of not becoming pregnant and contemplating the possibility of failure. Issues raised in the group were those such as 'feeling different', relationship difficulties, the sharing of knowledge about treatment and feelings of inadequacy.

In terms of DI, this type of therapeutic group format might be helpful for men and women, both separately and together. However, Goodman and Rothman (1984) acknowledge that DI was initially difficult to discuss in a group setting as they

suggest it exposes the male partner's 'defectiveness' and the woman's own feelings of shame. However once it was discussed the women gained understanding and acceptance from the group in terms of their fears about 'infidelity' and the 'wish for an idealised partner'.

Separate men and women's groups might enable more open discussions for example for the men on coming to terms with their infertility and for the women, the experience of the insemination and invasive investigations. From the results of this study and the fears expressed around secrecy, it would also be essential in groups of this kind to address issues of confidentiality. For those couples at the clinic who have not accessed support groups such as the 'DI Network', group therapy might provide the answers to some of their fears about telling the child and their families, thus easing their distress levels.

However, there is a clear dilemma where whilst there is the need to respect couples' choice, options must also be made available to them. This obviously requires a sensitive approach to couples, not endorsing only one 'right' answer in terms of telling or not. As this study has shown making the decision to tell your child and doing so, is not without its difficulties.

Consideration should also be given to the importance of involving the male partner in treatment, and in insemination, which this study has found to be an emotionally painful process for both partners. The implications of the insemination should be thought through, prior to its taking place in a safe environment, thus promoting more open dialogue between the couple and the clinicians.

Clearly the FAS is a useful clinical tool, and the higher scores indicating difficulties in adjustment were also found to be associated with higher levels of distress and anxiety. The FAS is a tool which would be useful to incorporate into clinical practice, in order to help clinicians and counsellors monitor couples who are more vulnerable, and who might need extra emotional support throughout treatment.

Edelmann and Connolly (1987. In Woollett, 1991) comment on the importance of addressing the emotional vulnerability of these patients, especially at their first clinic appointments. Screening couples at this stage would perhaps predict future distress. It is therefore important that tools such as the FAS and resources such as counselling (both implications and therapeutic) be directed to where it is most needed, and when it is most likely to be effective.

A useful point made by two participants in this study was in their experience of completing the questionnaires. This couple swapped their questionnaires, reading each other's responses, which promoted a discussion between them about aspects of the DI treatment. Perhaps the point made by this couple, that counselling in treatment could incorporate this kind questionnaire would enable the DI treatment to be undertaken in a more mutually supportive, and less threatening or isolating way.

"We found this a really useful experience as we could find out each others feelings about the treatment...it provoked a really good discussion about all areas of treatment between myself and my husband" (woman in treatment)

Clearly it is also important to work through individual emotional reactions to DI and to the professionals involved (Raphael-Leff, 1980). This is seen in the responses to open questions from participants in the study which focused on the personal

meanings of DI such as the insemination, the counselling, and the decision about telling the child or not.

4.5 CONCLUSION

Although the samples included in this research are clearly not representative of all couples who are undergoing or have undergone treatment, it perhaps begins to pave the way for more openness in this field. It is essential that couples have the opportunity to hear from couples who have told their child, the consequences of doing so, and the ways in which it is done. It is perhaps only then that some of the damaging stigma and secrecy surrounding all those involved in DI, the donor, consultants, recipient couple and any offspring can start to be dismantled. This study has illustrated the benefits of talking to others about DI, the majority not responding negatively, and making it easier to utilise support during what can be stressful treatment. As one male participant stated; “The more people I told, the easier it became”.

Research and resources need to be channelled into helping couples who endure the problems of infertility and do not conceive after DI treatment; thus helping them accept their infertility and move into other areas of their life. As Koval and Scutt (Scutt, 1990) suggest, the continual emphasis on a successful pregnancy for those undergoing many unsuccessful treatment cycles, “perpetuates the cycle of depression, despair, hope” (Scutt, 1990, p53.)

One of the confusions in the field of reproductive technologies and in maintaining psychological support for those who undertake treatments is reflected on by Shaw (in Davis & Fallowfield, 1991). As she points out:

“The impetus of reproductive innovations has raced ahead regardless of the size and complexity of the psychological dimensions associated with the state of childlessness”. (Shaw in Davis & Fallowfield, 1991 p171).

She also points to the difficulties currently faced in the NHS where doctors and nurses in fertility clinics may be faced with being both the “medical and emotional caretakers” of patients, as there is a shortage of trained psychologists or counsellors. So clearly as reproductive methods advance and couples are faced with an ever-increasing number of decisions, it is essential that emotional and psychological support be integrated at all stages. This might perhaps involve counselling in the initial stages at diagnosis, through the investigations, treatment and if the treatment fails. DI also calls for the need for ongoing support and advice for couples who do succeed in having children in this way and thinking about the future implications for the child. This needs to be integrated with the medical care of couples, as DI in particular arouses many ethical dilemmas, such as the extent of non-identifying information about the donor that a DI child and their parents have a right to. Due to the difficulties providing support for couples undergoing treatment it is also important to address the dilemma regarding how to offer counselling so that it is not seen as part of an assessment. This research has highlighted the different needs of couples and ideally one might envisage a service that can provide information, counselling, as well as the opportunities for couples to meet with other men and women undergoing treatment.

It is also important to address the feelings of the male partner throughout the DI process, increasing his involvement, and acknowledging his feelings about his infertility and any future child born as a result of DI. In particular, little is known

about how these families deal with, and speak about DI after the child has been born, so organisations such as the DI Network play an essential part in the arena of infertility and DI, providing information and resources for men and women and their families. However it is also worth considering how to provide support for couples who may be less well educated and who do not seek out organisations such as the DI Network.

Clearly the decision of secrecy or openness is not easy, and whilst there seems to be a move towards more openness in this field, this needs to be done carefully and sensitively, taking into account the personal difficulties for men and women who use DI. Openness and the path to breaking down the stigma and secrecy in the field of DI needs to be balanced with adequate resources and psychological support, taking into account at all times the needs of the family as a whole. For those couples who have tried DI treatment unsuccessfully, there needs to be more focused attention on the needs of this group and priority given to their psychological as well as medical needs. Finally, there is also a need to move away from polarising the two decisions regarding telling your child or not, as these decisions are by no means clear-cut. Both positions have their complications, and options must be made available for the couples to consider what is the 'best' decision for them and their families. Given that this is a field where the dynamics of DI treatment are challenging and anxiety levels approach clinical significance it is essential to address the psychological needs of men and women, both during treatment and afterwards, despite the outcome.

Perhaps as clinicians, psychologists and counsellors work hand in hand a fully comprehensive package of care can be provided, addressing the needs of all those who undertake DI treatment, not forgetting the needs of the potential child.

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APPENDICES

- 1. UCLH Ethics Committee Letter of Approval.**
- 2. Information Sheet for Participants.**
- 3. Consent Form for Participants.**
- 4. Recruitment Letter for Hospital Clinic Participants.**
- 5. Recruitment Letter for DI Network Participants.**
- 6. DI Network Newsletter Article.**
- 7. Hospital Anxiety and Depression Schedule (HADS).**
- 8. The Fertility Adjustment Scale (FAS).**
- 9. Questionnaire for Hospital Clinic Sample.**
- 10. Questionnaire for DI Network Members who were undergoing DI treatment.**
- 11. Questionnaire for DI Network Members who have a child.**



The University College London Hospitals

The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor André McLean

Please address all correspondence to:

Mrs Iwona Nowicka
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You do not have to take part in this study if you do not want to. If you do take part you may withdraw at any time without having to give a reason. Your decision to take part or not will not affect your care or management in any way.

Title of the Project

*Send out
→
file*

11 August 1997

Dr Myra Hunter
Clinical Psychologist
Sub Department of Clinical Health F
UCL
Gower Street
London WC1E 6BT

Dear Dr Hunter

97/0227 **The concerns and expectations of men and women undergoing donor insemination treatment**

Thank you very much for sending me the amendments to the above study. You may now proceed with your study.

Yours sincerely

Professor André McLean
Chairman

If you have any questions please contact Natasha Salter-Ling on 0171 380 7777 extension 5985.

Thank you for your help

YOU MAY KEEP THIS COPY OF THE INFORMATION SHEET

**CONFIDENTIAL
INFORMATION SHEET**

You are being invited to participate in a research project. The statement below explains what you will do if you agree to take part, it also explains what we hope to learn as a result of you taking part.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. Your decision to take part or not will not affect your care or management in any way.

Title of the Project

The concerns and expectations of men and women undergoing donor insemination (DI) treatment.

Explanation

We are carrying out a study looking at the concerns and expectations of men and women undergoing DI treatment. We are looking both at people who are currently in treatment and also those who now have a child through use of DI. Investigation and treatment of fertility difficulties can clearly be a distressing and stressful process. Our aim in this study is to find out what your concerns are at different points in the treatment and also to see what issues raised in implications counselling with the doctor you are most worried about. We are also interested in seeing what the concerns are if you have a child through DI. We hope that by learning more about the impact of donor insemination treatment we can see what psychological support might be offered.

We are asking men and women who attend the Reproductive Medicine Unit at UCLH for DI if they wish to participate by sending them a letter so they can 'opt in', they will then be sent a consent form and questionnaire and stamped addressed envelope. Members of the DI Network will also be invited to participate in the same way. All information given in the questionnaires will be confidential and will not be traced back to your hospital notes. The study does not involve any extra tests or investigations and will not alter your treatment in any way.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the joint UCL/UCLH Committees on the Ethics of Human Research.

If you have any questions please contact Natasha Salter-Ling on 0171 380 7777 extension 5985.

Thankyou for your help.

YOU MAY KEEP THIS COPY OF THE INFORMATION SHEET

Sub-Department of Clinical Health Psychology

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CONFIDENTIAL PARTICIPANT CONSENT FORM

Title of Project:

The concerns and expectations of men and women undergoing donor insemination treatment

Please read the following and delete the answer as appropriate:

- Have you read the information sheet on this study? Yes / No
- Have you had an opportunity to ask questions and discuss this study? Yes / No
- Have you received satisfactory answers to all your questions? Yes / No
- Have you received enough information about this study? Yes / No
- Have you been able to speak to an investigator responsible for this study? Yes / No
- Do you understand that you are free to withdraw from this study.....
- * at any time
- * without giving a reason for withdrawing
- * without affecting your future medical care

Do you agree to take part in this study?

If yes, please sign and date below.

Signed.....

Date

Name in Block Letters

Investigators signature

Investigators : Natasha Salter-Ling 0171 380 7777 extension 5985

Dr Myra Hunter

IF SIGNED PLEASE RETURN THIS WITH YOUR COMPLETED
QUESTIONNAIRE IN THE S.A.E.

The University College London Hospitals



University College London Hospitals is an NHS Trust incorporating The Eastern Dental Hospital, The Hospital for Tropical Diseases, The Maudsley Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabethan Gynaecological Hospital and Hospital St Wharfedale, Salford, and University College Hospital.



Sub-Department of Clinical Health Psychology

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Research on the concerns and expectations of men and women undergoing donor insemination treatment

Researchers at the Sub-department of Clinical Health Psychology, University College London are currently carrying out a study looking at couples' experience of donor insemination.

It is acknowledged that the investigation and treatment of fertility difficulties can be a distressing and stressful process. The aim of this research is to find out what your concerns are at different points in treatment. It is hoped that learning more about the impact of DI treatment will help to improve the psychological support offered.

Participating in this research would involve you and your partner each filling in a questionnaire and returning it to the researchers in a S.A.E.. All information given in the questionnaires will be confidential. It will not be traced back to your hospital notes. Your decision whether to take part or not will not affect your care and management in any way.

If you have any questions please contact Natasha Salter-Ling on 0171 380 7897 extension 5985.

June A. Valentine

Sister Valentine
Reproductive Medicine Unit

I am willing to take part in this research:-

My name:.....

My partner's name:.....

Address:.....
.....
.....

Telephone number:.....



The University College London Hospitals

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabeth Garrett Anderson Hospital and Hospital for Women, Soho, and University College Hospital.



DI NETWORK

PO Box 265
Sheffield S3 7YX

Newsletter Number 10
October 1997

NETWORK SPONSORS DI RESEARCH

As you may recall from our last newsletter a number of us have been outlining recent research into DI. To date, there has been very little research into the experiences of those undergoing DI or those who have had children with DI. The issue of openness and how children grow up with knowledge about DI has also been much discussed.

Over the summer, we have been in consultation with researchers from University College London who are carrying out a study looking at the concerns and expectations of men and women undergoing DI treatment. They have devised a questionnaire which we would like DI members to complete, and we include with this newsletter an invitation to take part in the study. The invitation has gone to all members of the DI network, however, the study is only for those who are undergoing DI or who have had children from egg donation. It does not include questions on sperm donation or expectations for children who have been born as a result of sperm donation. We do hope that future research will address these issues. The researchers would be very grateful to members who would like to take part in the study to return the enclosed reply slip and they will be happy to return a questionnaire to complete.

The research project and questionnaire has been approved by the DI steering committee and we would like to assure all members that any information they provide will be treated in the strictest of confidence.

We do hope you will be able to take part in the research, as it is in our interests and those of future members that our experiences are documented. The researchers at UCL are very happy to answer any queries you may have about the research, however, if you would rather talk to a member of the DI network who is taking part, then please contact either Mandy Pugh (0181 874 6681 - evenings) or Helena Pugh (0181 800 7826 - evenings) who will be happy to talk to you about the research. In addition, if you would like to take part in the study anonymously, then you can contact either Mandy or Helena and they will be happy to send you a questionnaire which you can complete without giving any personal details. The results from this study will be reported back to the DI network and we hope will be presented at a future DI network meeting.

DONOR CHARITY PLANS INCH AHEAD

Prospects for the planned national charity to help egg and sperm donors to come forward continue to look bright. A constitution has now been prepared and an application is being submitted to the Department of Health for funding. The proposed charity has the backing of a wide range of sponsors, including the Royal Colleges of Obstetrics and Gynaecology, Medicine and Nursing, the British Fertility Society, the British Andrology Society, the British Infertility Counselling Association, and PROGRESS (the genetics education trust). But the key organisations will be the three patient support bodies, Issue, Child and DI Network, who are to nominate the founder trustees.

It is intended that the National Gamete Donation Trust will initially employ a full time coordinator and assistant, possibly to be based in offices next to those of Issue in Walsall. It is unlikely that the new body will be up and running until mid 1998.

WOULD YOU JOIN THE NETWORK'S CONTACT LIST?

There are 25 member families on the Network's contact list - people who have said they are happy to be phoned or contacted by new members - or old members - looking for support. This forms a much appreciated part of the Network's function. Some people say that just seeing the names and numbers of contactable people in their situation gives them a confidence boost.

Steering Group member Jane Ellis is about to up-date the list. Please let her know if you would be prepared to join the list.

Please read each item and place a tick on the line alongside the reply that comes closest to how you have been feeling in the past few weeks. Don't take too long over your replies: your immediate reaction to each item will probably be a more accurate response.

I feel tense or "wound up":

Most of the time _____
 A lot of the time _____
 Occasionally _____
 Not at all _____

I feel as if I am slowed down:

Nearly all the time _____
 Very often _____
 Sometimes _____
 Not at all _____

I still enjoy the things I used to enjoy:

Definitely as much _____
 Not quite as much _____
 Only a little _____
 Hardly at all _____

I get a frightened feeling like "butterflies" in my stomach:

Not at all _____
 Occasionally _____
 Quite often _____
 Very often _____

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly _____
 Yes, but not too badly _____
 A little, but it doesn't worry me _____
 Not at all _____

I have lost interest in my appearance:

Definitely _____
 I don't take as much care as I should _____
 I may not take quite as much care _____
 I take just as much care as ever _____

I can laugh and see the funny side of things:

As much as I always could _____
 Not quite so much now _____
 Definitely not so much now _____
 Not at all _____

I feel restless as if I have to be on the move:

Very much indeed _____
 Quite a lot _____
 Not very much _____
 Not at all _____

Worrying thoughts go through my mind:

A great deal of the time _____
 A lot of the time _____
 From time to time but not too often _____
 Only occasionally _____

I look forward with enjoyment to things:

As much as I ever did _____
 Rather less than I used to _____
 Definitely less than I used to _____
 Hardly at all _____

I feel cheerful:

Not at all _____
 Not often _____
 Sometimes _____
 Most of the time _____

I get sudden feelings of panic:

Very often indeed _____
 Quite often _____
 Not very often _____
 Not at all _____

I can sit at ease and feel relaxed:

Definitely _____
 Usually _____
 Not often _____
 Not at all _____

I can enjoy a good book or radio or TV programme:

Often _____
 Sometimes _____
 Not often _____
 Very seldom _____

Thank you for your help

DIRECTIONS

Please rate the extent to which you agree or disagree with each statement using the scale below.

1	2	3	4	5	6
Strongly disagree	Moderately disagree	Mildly disagree	Mildly agree	Moderately agree	Strongly agree

Please read each statement carefully and then put your rating (1 - 6) in the space given. For example, if you moderately disagree with a statement write "2". Please answer according to how you feel at the moment. Do not spend too much time on any one item, rather give your first impression. If you already have a child, please answer the questions in relation to having another child.

1. I will continue with investigations/treatment until I succeed in having a child* _____
2. There are both advantages and disadvantages to having a child _____
3. I can't plan for the future until I know for certain whether or not I can have a child _____
4. I can talk to my partner about the possibility of not having a child _____
5. I want a child of my own more than anything else in life _____
6. I have made plans for a possible future life without a child _____
7. I seem to live my life from month to month _____
8. I will always feel unfulfilled if I am unable to have my own child _____
9. I think I could adjust to a future life without a child _____
10. I make sure that I carry on with my normal life activities _____
11. I can't imagine a future without a child _____
12. I think life could be rewarding either with or without children _____

**QUESTIONNAIRE ABOUT YOUR DONOR INSEMINATION
TREATMENT**

study no.....

Section 1

Please answer the questions below which are about you and your partner and the donor insemination treatment.

Male / Female (Please circle as appropriate)

Age Date of birth.....

Highest qualification achieved

Current / Most recent occupation

Are you working at the moment ? Yes / No (Please circle as appropriate)

full time part time unemployed not working responsible for childcare

How would you describe your ethnic background? (please tick)

White

Black

Asian

Other (please specify)

We would like you to think about your current experience of donor insemination treatment when answering the questions below.

1) How long have you and your partner been trying to have a baby?

.....years

2) Do you have a child/children already? Yes / No

If Yes was this with (please circle as appropriate):

Donor insemination / Other fertility treatments / Without fertility treatment

3) When did you and your partner first attend the donor insemination clinic?

.....month year

4) How many donor insemination treatments (cycles) have you (or your partner) had?

.....treatments/cycles

5) Have you been given a reason for you and your partners fertility difficulty?

Yes / No / Don't know

If Yes, what is it.....

6) Approximately how long did you and your partner wait before deciding to attempt donor insemination treatment?

.....years /months

Why did you wait for that length of time?

.....
.....

7) Please circle a number on the scale below to show how distressed you feel at present about you and your partners difficulty in having a baby?

1----2----3----4----5----6----7----8----9----10
not at all very

8) How distressed do you feel your partner is at present about the difficulty in having a baby? (please circle)

1----2----3----4----5----6----7----8----9----10
not at all very

9) To what extent do you feel the DI treatment interferes with your daily routine or lifestyle? (please circle)

1----2----3----4----5----6----7----8----9----10
not at all very much

Please state in what ways.....
.....
.....
.....

10) How many more DI treatment cycles do you expect that you (or your partner) will have?

(please circle one of the following)

1 cycle up to 3 cycles up to 6 cycles up to 9 cycles up to 12 cycles over 12 cycles

Section 2

Many couples undergoing donor insemination treatment feel quite anxious and upset about their fertility difficulties and the need to seek treatment. The questions below are about your feelings, about the treatment and any concerns you might have about the future.

11) Please describe what your main concerns are at the moment in relation to your fertility difficulties and its treatment

- a).....
- b).....
- c).....
- d).....

12) How concerned are you now about the following issues? Please circle your answers on the scales below.

Telling your family about your donor insemination treatment.

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The characteristics of the donor

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Telling your child about DI (if treatment is successful)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The child's right to seek further information about the donor when he/she is eighteen

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The risk of multiple births

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Getting pregnant

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

How you might feel about your child (if treatment is successful)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Whether your child from DI treatment will feel as if s/he is yours and your partners

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The effect of having DI treatment on your relationship with your partner

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The appearance of your child

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

How closely the donor matched the male partner's appearance

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The relationship between your DI child and non DI children in your family at present (if applicable)

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The medical procedure of donor insemination

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

Do you have any other concerns? Please state below

.....
.....
.....
.....
.....

13) Do you feel you have enough information about donor insemination treatment and other related issues?

Yes / No

If no what would you like to know more about?

.....
.....
.....

14) Which of the following concerns do you remember discussing with the doctor before beginning donor insemination treatment?

(please tick all those that apply)

- a) Information about the medical procedure
- b) Information about the donor
- c) Information on the process of matching donors
- d) The issue of storage of sperm for future siblings
- e) Information about possible outcomes
- f) Information about telling the child
- g) Discussion about the pros/cons of telling a child its origins
- h) Discussion about how to tell the child
- i) Information about telling your families
- j) Discussion about the pros/cons of telling your families
- k) Discussion about telling other people
- l) Opportunity to talk about your feelings

15) Looking back, were there other issues that you would have liked to discuss with the doctor before treatment? Yes / No (please circle as necessary)

If Yes, what were these issues?

.....
.....
.....

16) Would you like to see a counsellor to discuss your concerns? (circle as necessary)

Yes /No

If yes On your own / With your partner (please circle)

17) Who have you told about you and your partner coming for donor insemination treatment?

(please circle **all** those that apply)

Your family Your partners family Friends Work colleagues Your boss Nobody

Other(please state)

How did they react?

.....
.....
.....

18) If treatment is successful do you plan to tell the child about the DI procedure?

Yes / No/ Don't know (please circle as necessary)

What are your reasons for this?

.....
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.....
.....

19) Please estimate how likely it is that you and your partner will conceive through DI (please circle on the scale below)

1----2----3----4----5----6----7----8----9----10

not at all likely

extremely likely

20) So far, has your experience of DI treatment been better / same / worse than expected? Better Same Worse (please circle as necessary)

Please state in what way it has been better or worse.....
.....
.....

21) Finally, what has been the most difficult thing about donor insemination treatment?

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Finally do you have any other comments about the process of fertility problems and DI treatments?

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*We greatly appreciate your participation in this research and hope that the results can play a part in informing and improving donor insemination services. Please complete the attached HADS & FAS scale and return your questionnaires in the SAE. Thank you for taking the time to complete this questionnaire if you have any further questions or would like to discuss any of your concerns please contact:
Natasha Salter-Ling 0171 380 7777 extension 5985*





CAMDEN & ISLINGTON

Community Health Services NHS Trust

Your Partner for Health

Sub Department of Clinical Health Psychology

University College London

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Tel:0171 380 7895

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FERTILITY QUESTIONNAIRE

CONFIDENTIAL

We are carrying out research into the experience of couples who have undergone donor insemination treatment. We are asking all couples who are members of the DI Network who are having treatment to complete the following questionnaire. All information will be treated with absolute confidentiality.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason.

If you would like to take part in this study, please complete the following questionnaire and consent form and send it back to us in the stamped addressed envelope enclosed. It is important that you and your partner fill in a questionnaire each separately. If you have any questions please contact Natasha on the number below.

Thank you.

(Natasha Salter-Ling 0171 380 7777 extension 5985)

c/v/din

**QUESTIONNAIRE ABOUT YOUR DONOR INSEMINATION
TREATMENT**

study no.....

Section 1

Please answer the questions below which are about you and your partner and the donor insemination treatment.

Male / Female (Please circle as appropriate)

Age Date of birth.....

Highest qualification achieved

Current / Most recent occupation

Are you working at the moment ? Yes / No (Please circle as appropriate)

full time part time unemployed not working responsible for childcare

How would you describe your ethnic background? (please tick)

White

Black

Asian

Other (please specify)

We would like you to think about your current experience of donor insemination treatment when answering the questions below.

1) How long have you and your partner been trying to have a baby?

.....years

2) Do you have a child/children already? Yes / No

If Yes was this with (please circle as appropriate):

Donor insemination / Other fertility treatments / Without fertility treatment

3) When did you and your partner first attend the donor insemination clinic?

.....monthyear

4) How many donor insemination treatments (cycles) have you (or your partner) had?

.....treatments/cycles

5) Have you been given a reason for you and your partners fertility difficulty?

Yes / No / Don't know

If Yes, what is it.....

6) Approximately how long did you and your partner wait before deciding to attempt donor insemination treatment?

.....years /months

Why did you wait for that length of time?

.....
.....

7) Please circle a number on the scale below to show how distressed you feel at present about you and your partners difficulty in having a baby?

1----2----3----4----5----6----7----8----9----10
not at all very

8) How distressed do you feel your partner is at present about the difficulty in having a baby? (please circle)

1----2----3----4----5----6----7----8----9----10
not at all very

9) To what extent do you feel the DI treatment interferes with your daily routine or lifestyle? (please circle)

1----2----3----4----5----6----7----8----9----10
not at all very much

Please state in what ways.....
.....
.....
.....

10) How many more DI treatment cycles do you expect that you (or your partner) will have?

(please circle one of the following)

1 cycle up to 3 cycles up to 6 cycles up to 9 cycles up to 12 cycles over 12 cycles

Section 2

Many couples undergoing donor insemination treatment feel quite anxious and upset about their fertility difficulties and the need to seek treatment. The questions below are about your feelings, about the treatment and any concerns you might have about the future.

11) Please describe what your main concerns are at the moment in relation to your fertility difficulties and its treatment

- a).....
- b).....
- c).....
- d).....

12) How concerned are you now about the following issues? Please circle your answers on the scales below.

Telling your family about your donor insemination treatment.

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The characteristics of the donor

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

Telling your child about DI (if treatment is successful)

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The child's right to seek further information about the donor when he/she is eighteen

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The risk of multiple births

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

Getting pregnant

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

How you might feel about your child (if treatment is successful)

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

Whether your child from DI treatment will feel as if s/he is yours and your partners

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The effect of having DI treatment on your relationship with your partner

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The appearance of your child

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

How closely the donor matched the male partner's appearance

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The relationship between your DI child and non DI children in your family at present (if applicable)

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The medical procedure of donor insemination

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

Do you have any other concerns? Please state below

.....
.....
.....
.....
.....

13) Do you feel you have enough information about donor insemination treatment and other related issues?

Yes / No

If no what would you like to know more about?

.....
.....
.....

14) Which of the following concerns do you remember discussing with the doctor before beginning donor insemination treatment?

(please tick all those that apply)

- a) Information about the medical procedure
- b) Information about the donor
- c) Information on the process of matching donors
- d) The issue of storage of sperm for future siblings
- e) Information about possible outcomes
- f) Information about telling the child
- g) Discussion about the pros/cons of telling a child its origins
- h) Discussion about how to tell the child
- i) Information about telling your families
- j) Discussion about the pros/cons of telling your families
- k) Discussion about telling other people
- l) Opportunity to talk about your feelings

15) Looking back, were there other issues that you would have liked to discuss with the doctor before treatment? Yes / No (please circle as necessary)

If Yes, what were these issues?

.....
.....
.....

16) Would you like to see a counsellor to discuss your concerns? (circle as necessary)

Yes /No

If yes On your own / With your partner (please circle)

17) Who have you told about you and your partner coming for donor insemination treatment?

(please circle all those that apply)

Your family Your partners family Friends Work colleagues Your boss Nobody

Other(please state)

How did they react?

.....
.....
.....

18) If treatment is successful do you plan to tell the child about the DI procedure?

Yes / No/ Don't know (please circle as necessary)

What are your reasons for this?

.....
.....
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.....
.....

19) Please estimate how likely it is that you and your partner will conceive through DI (please circle on the scale below)

1----2----3----4----5----6----7----8----9----10

not at all likely

extremely likely

20) So far, has your experience of DI treatment been better / same / worse than expected? Better Same Worse (please circle as necessary)

Please state in what way it has been better or worse.....

.....
.....

21) Finally, what has been the most difficult thing about donor insemination treatment?

.....
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.....

Finally do you have any other comments about the process of fertility problems and DI treatments?

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*We greatly appreciate your participation in this research and hope that the results can play a part in informing and improving donor insemination services. Please complete the attached HADS & FAS scale and return your questionnaires in the SAE. Thank you for taking the time to complete this questionnaire if you have any further questions or would like to discuss any of your concerns please contact:
Natasha Salter-Ling 0171 380 7777 extension 5985*





CAMDEN & ISLINGTON

Community Health Services NHS Trust

Your Partner for Health

**Sub Department of Clinical Health Psychology
University College London
Gower Street
LONDON WC1E 6BT
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Fax:0171 916 1989**

FERTILITY QUESTIONNAIRE
CONFIDENTIAL

We are carrying out research into the experience of couples who have undergone donor insemination treatment. We are asking all couples who are members of the DI Network and have a child, or a number of children, as a result of DI to complete the following questionnaire. This will involve thinking back to the most recent donor insemination treatment you and your partner had and any issues that you may be concerned about now. We hope that results gained from this research will be useful in further informing DI practice and improving services. All information will be treated with absolute confidentiality.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason.

If you would like to take part in this study, please complete the following questionnaire and send it back to us in the stamped addressed envelope enclosed. It is important that you and your partner fill in a questionnaire each separately. If you have any questions please contact Natasha on the number below.

Thank you.

(Natasha Salter-Ling 0171 380 7777 extension 5985)

c/c/din

**QUESTIONNAIRE ABOUT YOUR DONOR INSEMINATION
TREATMENT**

study no.....

Section 1

Please answer the questions below which are about you and your partner and the donor insemination treatment.

- Male / Female (Please circle as appropriate)
Age Date of birth.....
Highest qualification achieved
Current / Most recent occupation
- Are you working at the moment? Yes / No (Please circle as appropriate)
full time part time unemployed responsible for child care
- How would you describe your ethnic background? (please tick)
White....
Black
Asian....
Other (please specify).....

We would like you to think about your most recent experience of donor insemination when answering these questions

- 1) How old is your child that you had most recently as a result of donor insemination treatment?years
- 2) How long had you and your partner been trying to have a baby without the use of DI?years
- 3) Did you have a child/children already? Yes / No
If Yes was this with (please circle as appropriate):
Donor insemination / Other fertility treatments / Without fertility treatment
- 4) How many donor insemination treatments (cycles) did you (or your partner) have to achieve your most recent pregnancy?
.....treatments/cycles
- 5) Have you been given a reason for you and your partners fertility difficulty?
Yes / No / Don't know
If Yes, what is it?.....
- 6) Approximately how long did you wait before deciding to attempt donor insemination treatment for your most recent child?
.....years / months

Why did you wait for that length of time?

.....
.....
.....

7) Please circle a number on the scale below to show how distressed you feel at present about the difficulties you and your partner had in having a baby

1----2----3----4----5----6----7----8----9----10
not at all very

8) How distressed do you feel your partner is about the past difficulty in having a baby? (please circle)

1----2----3----4----5----6----7----8----9----10
not at all very

9) To what extent did you feel the DI treatment interfered with your daily routine or lifestyle? (please circle)

1----2----3----4----5----6----7----8----9----10
not at all very much

Please say in what ways it interfered

.....
.....
.....

10) Before treatment how many DI treatment cycles did you expect that you (or your partner) would have?

(please circle one of the following)

1 cycle up to 3 cycles up to 6 cycles up to 9 cycles up to 12 cycles over 12 cycles

Section 2

Many couples undergoing donor insemination treatment feel quite anxious and upset about their fertility difficulties and the need to seek treatment. The questions below are about your feelings about the treatment you had and any concerns you might have.

11) Please describe what your main concerns are now in relation to your fertility difficulties and the DI treatment you had.

- a).....
 - b).....
 - c).....
 - d).....
-

12) How concerned are you now about the following issues? Please circle your answers on the scales below.

Telling your family you had donor insemination treatment.

1----2----3----4----5----6----7----8----9----10
not at all very concerned
concerned

The characteristics of the donor

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Telling your child/children about DI

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Your child's/children's right to seek further information about the donor when he/she is eighteen

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

How you feel about your child/children

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Whether your child/children from DI treatment feels to you as if s/he is yours and your partners

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The effect of having had DI treatment on your relationship with your partner

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The appearance of your child/children

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

How closely the donor matched the male partner's appearance (if applicable)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

The relationship between your DI child and non DI children in your family (if applicable)

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
not at all very concerned
concerned

Do you have any other concerns? Please state below

.....
.....
.....
.....
.....
.....

12) Do you feel you had enough information about donor insemination and other related issues?

Yes / No

If no what would you have liked to have known more about?

.....
.....
.....
.....

13) Which of the following concerns do you remember discussing with the doctor before beginning donor insemination treatment?

(please tick all those that apply)

- a) Information about the medical procedure
- b) Information about the donor
- c) Information on the process of matching donors
- d) The issue of storage of sperm for future siblings
- e) Information about possible outcomes
- f) Information about telling the child
- g) Discussion about the pros/cons of telling a child its origins
- h) Discussion about how to tell the child
- i) Information about telling your families
- j) Discussion about the pros/cons of telling your families
- k) Discussion about telling other people
- l) Opportunity to talk about your feelings

14) Looking back, were there other issues that you would have liked to discuss with the doctor before treatment? Yes / No (please circle as necessary)

If Yes, what were these issues?

.....
.....
.....
.....
.....

15) Did you see a counsellor to discuss your concerns? (please circle as necessary)

Yes / No (if No, go to question 17)

If yes how many sessions?

On your own/ With your partner Before DI / After DI

(Now go to question 18)

