



The Women's Health Council
Comhairle Sbláinte na mBan

Infertility and Its Treatments

A Review of Psycho-social Issues



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A Review of Pyscho-social Issues

2009





A dandelion is a universal symbol for fertility - the dozens of seeds released by each flower head represent fertility and abundance. The seeds' journey illustrates a time of letting go, of starting something new

The Women's Health Council

The Women's Health Council is a statutory body established in 1997 to advise the Minister for Health and Children on all aspects of women's health.

The mission of the Women's Health Council is to inform and influence the development of health policy to ensure the maximum health and social gain for women in Ireland. Its membership is representative of a wide range of expertise and interest in women's health.

The Women's Health Council has five functions detailed in its Statutory Instruments:

1. Advising the Minister for Health and Children on all aspects of women's health
2. Assisting the development of national and regional policies and strategies designed to increase health gain and social gain for women.
3. Developing expertise on women's health within the health services.
4. Liaising with other relevant international bodies which have similar functions as the Council.
5. Advising other Government Ministers at their request.

The work of the Women's Health Council is guided by three principles:

- equitably to the diverse needs and situations of women.
- Quality in the provision and delivery of health services to all women throughout their lives.
- Relevance to women's health needs.

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Members of NISIG included the relative lack of counselling available as one of their main complaints in relation to treatment services and 75% of couples who received counselling found it beneficial.

(CAHR, 2005)

One: Introduction

Infertility is a medical and social condition that can cause considerable social, emotional and psychological distress. It is estimated to affect one in six couples in Ireland (CAHR, 2005); however, it is still a topic that is not widely discussed or for which help is easily accessible.

This report aims to provide an overview of the range of psychological, emotional, social and practical difficulties that women affected by fertility problems often encounter. It is to act as a companion publication to *Infertility Treatments for Women: a review of bio-medical evidence* (WHC, 2009), which focuses on medical interventions, to provide a more holistic portrayal of the experience of infertility and its treatments.

Following best practice recommendations, this review will focus on couples and take a gender-sensitive approach. Nevertheless, the experiences and needs of women will be more prominent for two reasons: because that is the remit and area of expertise of the Women's Health Council, but also because, as it will be shown, women are inevitably the focal point when matters of fertility and reproduction are investigated. Still, this focus will also be questioned and its repercussions analysed. While we are conscious that same-sex couples as well as single men and women may be affected by infertility, this report will deal mainly with the experience of heterosexual couples, reflecting the literature available and its heterosexual bias. However, issues of discrimination and access will be addressed.

Finally, while this review will touch on the current service provision and the lack of regulation in this field, it will not revisit the ethical and legal debate on the status of the embryo in Ireland or universally. Ethical and legal matters have been amply considered by the Commission on Assisted Human Reproduction (2005), whose recommendations we welcomed and hope to see implemented shortly.

Two: Infertility

2.1 General Background

Infertility is medically defined as a lack of conception following at least one year of unprotected sexual intercourse (WHO, 2009). The term 'subfertility' is often preferred to describe any form of reduced fertility that results in a prolonged or unwanted lack of conception (Gnoth *et al.*, 2005). It is estimated that a third of infertility cases are caused by a male factor, such as low sperm count. Almost another third are linked to a female factor, such as blocked fallopian tubes. The remainder consists of either a combination of both male and female factors (17% of cases), or unexplained infertility (19% of cases) (HFEA, 2007/2008).

While the evidence is contradictory on infertility trends, there is a perception that the rate of infertility is on the increase because of social reasons, e.g. a desire to delay parenthood to pursue career and financial security, and an increase in obesity and sexually transmitted infections (ESHRE, 2008). Improved diagnostics have also contributed to this perception (Hardy and Makuch, 2002). It is estimated that one in six Irish couples experience infertility at some point in their lives (CAHR, 2005), and this statistic is shared by most of the Western world (HFEA, 2005; Boivin *et al.*, 2007). Because of the scale of the problem across the globe, the World Health Organisation has called for the recognition of infertility as a public health issue worldwide (Fathalla, 2002).

In developed countries, studies show that approximately 50% of those affected seek medical care, and this percentage has remained stable over the last number of years (Schmidt *et al.*, 1995; Schmidt, 2006; White *et al.*, 2006; Boivin *et al.*, 2007; Moreau *et al.*, 2008). Information on the impact of fertility problems is primarily gleaned from research carried out in clinic settings and participants tend to be highly educated, urban, and of 'white' ethnic origin (Greil, 1997; Throsby, 2004; Moreau *et al.*, 2008). Therefore the experience of those who neither seek nor receive treatment is very poorly documented. It is plausible that for some their subfertility does not represent a problem and they do not feel the need to take any steps to address it. Others might lack the necessary information and resources to access treatment. Finally, others might feel that treatment would not be available to them because of their marital status, sexual orientation or religious beliefs. Some of these issues will be discussed further in the next chapters.

Whether infertility should be designated as a chronic health condition or a disability is still unclear, and it is not the purpose of this paper to delve into the intricacies of this debate. What is clear is that some patients do perceive the suffering from infertility as very real, and infertility is generally recognised as a source of diminished health and social well-being (Cook *et al.*, 2003; WHO, 2009). The literature consistently indicates that infertility is a condition that may cause significant pain and distress and which many people go to great lengths to overcome.

Infertility and its treatment can have a considerable impact on a person's quality of life and infertility problems can be among the most upsetting experiences in people's lives (Fekkes *et al.*, 2003). In fact, infertility has been ranked as one of the great stressors in life, comparable to divorce and death in the family (Holter *et al.*, 2006) and many authors have highlighted the similarities between coming to terms with infertility and the grieving process (Woods *et al.*, 1991; Burns, 2007; Peterson *et al.*, 2007). Others have pointed out that, unlike grieving because of bereavement, the grieving caused by infertility does not follow a sequential pattern, but it is recurrent and triggered by life events, the birth of other people's children and grandchildren, as well as the cyclic nature of the menstrual cycle (Woods *et al.*, 1991; Wirtberg *et al.*, 2007; McCarthy, 2008). Therefore, infertility has been more aptly described as a model of 'chronic sorrow' (Unruh and McGrath, 1985 in Woods *et al.*, 1991). The concept of 'disenfranchised grief' has also been used to describe the experience of loss without the socially recognised right to grieve (Doka, 1989 in Bergart, 2000).

A critical review of literature on infertility and its effects identified the themes below as dominant in research findings:

- infertility as a central focus for identity, especially for women
- feelings of loss of control and attempts to regain control
- feelings of defectiveness and reduced competence, especially for women
- perceived lack of status and ambiguity
- stress on marital and sexual relations at the same time that there exists a counter-tendency for infertility to 'pull couples together'
- feelings of alienation from the 'fertile world'
- a sense of social stigma
- difficulty of dealing with meaning of infertility in own life
- immersion in the treatment process
- stressful nature of the treatment process itself
- strained relationships with health care providers (Greil, 1997).

The effects of infertility and its treatment have also been poignantly described as a series of losses:

- loss of relationship with spouse
- loss of relationship with the social network
- loss of health and sexual pleasure
- loss of status and/or prestige
- loss of self-esteem
- loss of confidence and/or control
- loss of security
- loss of hope (Baor and Blickstein, 2005).

Most of these themes will be covered in more detail in the following sections. From this list, however, it is clear that infertility can have a significant impact on many aspects of a person's life and sense of identity.

"The physical and psychological burden the infertile couple are willing to go through, and the financial cost the couples are willing to pay if they can afford it, attest to the high ranking of infertility as a perceived burden of disease"

(Fathalla, 2002: 5).

2.2 Societal Pressures

While a deeply private, often hidden, experience, fertility is intrinsically linked with our social identity. Parenthood is perceived in most cultures as a central developmental milestone towards adulthood (Baor and Blickstein, 2005). Infertility, therefore, can cause a major disruption in people's lives because it interferes with the established and desired lifecycle (Becker, 1997; 2000).

It is recognised that the desire to have children is universal and that most couples have life plans that include children (Boivin *et al.*, 2007). Nevertheless, societal expectations also play a role in the desire to procreate, and where childbearing is a societal and cultural imperative, unintentionally childless couples feel even more isolated by their situation (Baor and Blickstein, 2005). Considering Ireland's strong pro-natalist culture and the tradition of large families (Hilliard, 2007; Fahey and Field, 2008), it is fair to assume that couples who are experiencing fertility problems in Ireland might feel excluded from the predominant experience and isolated in their delay or failure to procreate. In a survey among its members, the National Infertility Support and Information Group (NISIG) found that 87% reported that society put them under pressure because they had no children (CAHR, 2005)¹. Many respondents also found it difficult to discuss infertility with their family (63%) and friends (58%), pointing to the isolating effect of this condition.

In Ireland, while family size has considerably diminished over the last decade (Hilliard, 2007; Fahey and Field, 2008), it is still very unusual, and often perceived as undesirable, to have one child, who is usually referred to as an 'only' child. This pressure to have at least two children might also play a part in couples seeking treatment to overcome secondary infertility.

¹ While this is a survey with a small sample size of 129 participants, it is to date the only published information available on the experiences of people affected by infertility in Ireland. An in-depth longitudinal study of 34 couples undergoing IVF treatment is due to be completed in Autumn 2009 by Cotter and Mahon.

2.3 Psychological and Emotional Repercussions of Infertility

As already seen, infertility can cause considerable distress. Often cited consequences of infertility are: depression, anxiety, sexual anxiety/difficulty, relationship problems with partner, family and friends, and an increased sense of self-blame and guilt (Monach, 2005; Klock, 2008). Feelings of anger, bitterness, guilt, denial and isolation have also been found among Irish men and women experiencing this problem (CAHR, 2005). While most infertile individuals do not experience severe or clinically significant distress, a small portion do (Burns, 2007). There is also some evidence that shows that for both genders unexplained infertility is harder to cope with than when a diagnosis is reached (Verhaak *et al.*, 2007).

The occurrence of depression is well documented. Fortunately, for the majority of couples it is also relatively short-lived (Klock, 2008). Studies show that increased depression levels are common in infertile women and these usually peak between the second and third year of infertility (Peterson *et al.*, 2007). Anxiety is also a common consequence of infertility, usually manifesting itself through worry, restlessness, difficulty concentrating and fatigue (Peterson *et al.*, 2007). Couples, and especially women, also often blame past behaviours, such as sexual indiscretions, sexually transmitted infections or abortions, for their infertility, further compounding their stress and anxiety (Cosineau and Domar, 2007; Klock, 2008).

A couple's relationship often suffers because of fertility problems, and many report that the loss of spontaneity linked to intercourse timed to facilitate conception can have a considerable negative impact on desire and sexual function. However, many couples also experience infertility as a life-crisis that brings them together and strengthens their relationship (Cosineau and Domar, 2007; Peterson *et al.*, 2007; Klock, 2008; Schmidt, 2009). Eighty percent of Irish couples surveyed by NISIG claimed that their infertility problems had brought them closer to their partner; however, 53% also felt that the sexual relationship had suffered because of them (CAHR, 2005).

The isolating nature of infertility has already been commented upon, depriving couples of important social supports when they badly need them. Studies have found that one of the most difficult aspects to negotiate for infertile women is engaging with their social environment, such as dealing with feelings of jealousy or envy when learning of other women's pregnancies or being in the presence of infants and children (Cosineau and Domar, 2007).

Table 1 below summarises the various psycho-social repercussions of infertility.

Emotional effects	<ul style="list-style-type: none"> - Grieving and depression - Anger and frustration - Guilt - Shock and denial - Anxiety
Loss of control	<ul style="list-style-type: none"> - Loss of control over activities, body, emotions - Inability to predict and plan future - Loss of health - Loss of security (about a predictable future)
Effects on self-esteem, identity & beliefs	<ul style="list-style-type: none"> - Loss of self-esteem and self-confidence, feelings of inadequacy - Identity problems or shifts, loss of status or prestige - Changes in world views
Social effects	<ul style="list-style-type: none"> - Effects on marital interactions and satisfaction (positive and negative) - Effects on sexual functioning - Different social network interactions, changes in relationships with network members, loneliness, embarrassment
Loss of a (potential) relationship	<ul style="list-style-type: none"> - Loss of fantasy or hope of fulfilling an important fantasy - Loss of something or someone of great symbolic value - Loss of future and past in one person

Table 1. *Observed psychological effects of infertility (Burns, 2007)*

2.4 Key Issues

2.4.1 Information and Support

Despite infertility being a relatively common problem, people affected by it often believe it to be rare and find themselves feeling isolated from family and friends. An increase in public awareness and information is therefore crucial in order for couples to feel supported during their difficulties. Reducing the stigma and secrecy that surrounds fertility problems will enable couples to feel less isolated in their plight, and better able to discuss their problems with both their social network and with health professionals. Information on where to access support should also be more readily available. (For information and resources, see Section 8 of this report).

2.4.2 Prevention

Considering the widespread nature of fertility problems, it is essential to disseminate information on the main known causes of fertility problems and any preventative measures in relation to them. The Women's Health Council's biomedical review provides detailed information in this regard (WHC, 2009). More relevant to this report is the issue of how social and cultural pressures might also affect people's reproductive capacity. Maternal age is considered the most important determinant of conception, and much attention has been dedicated in the public arena to the increasing age of first time mothers. While women are often criticised for 'waiting too long', they often feel compelled to wait until their career is well established for fear of experiencing discrimination at work because of pregnancy or consequent caring responsibilities. Likewise, financial concerns also play a part in this delay, with couples wishing to feel secure in their employment and housing arrangements before embarking on parenthood. Therefore, much could be done to promote younger motherhood through policy measures to support parents economically and socially, for example by strengthening measures to combine work and family responsibilities (WHC, 2005; Soini, 2006).

Three: Infertility Treatments

While prevention is key, many couples will still be affected by fertility problems and will choose to seek treatment to overcome them. Over the last few decades technology has made huge leaps in the treatments available, which are now commonly referred to as 'assisted reproductive technologies' (ART). This report's sister publication *Infertility Treatments for Women: a review of bio-medical evidence* provides a comprehensive discussion of ART and a review of their effectiveness (WHC, 2009). This analysis, on the other hand, focuses on their repercussions on the health of the women and men who avail of them. While a gender analysis of their impact will follow later, for the moment it will suffice to say that women are the main recipients of interventions due to their biological role in pregnancy and childbirth and the paucity of research into the male reproductive system (Cook *et al.*, 2003; Deech and Smajdor, 2007). This unequal burden of care is not without its implications for both genders as we will see later. This review will focus mainly on IVF, which is the most common assisted reproductive procedure carried out nationally, and the most researched in terms of its psychosocial effects.

A significant aspect of infertility treatments in Ireland is their controversial nature due to the unresolved questions about the legal status of the embryo (Cotter, 2009). ART often involves the storage and disposal of 'excess' embryos, which is against the teachings of the Catholic Church, the country's most prominent and influential religion. The Catholic doctrine is also reflected in the Ethical Guidelines of the Medical Council which state that "any fertilised ovum must not be deliberately destroyed" (2004: 36)². While this review will not discuss the complex ethical and moral issues involved, it is important to note that the unresolved question of the legal status of the embryo has practical repercussions for service provision and might also negatively affect patients' emotional and psychological well-being.

3.1 Brief overview of services

In Ireland, general practitioners (GPs) are usually the first port of call for couples experiencing problems in this area (CAHR, 2005). They provide a diagnostic and referral service. In a survey of NISIG members, 78% of them had found their GPs helpful. However, at the moment no national best practice guidelines are available to general practitioners in relation to the diagnosis and treatment of infertility and this is something that should be rectified (CAHR, 2005).

² The revised seventh edition of the Medical Council's Guide to Ethical Conduct and Behaviour is due out shortly.

The vast majority of investigations and treatments are carried out in fertility clinics (for more information on these, see section 8). There are ten clinics operating in Ireland at the moment. However, only six of them are members of the European Society of Human Reproduction and Embryology reporting system (Nyboe Andersen *et al.*, 2009) and one provides only NaPro Technology (Natural Procreative Technology) treatment³. While geographical access is not consistent, most major urban centres are covered. Nevertheless, the limited choices in service providers and distance from the clinic were some of NISIG members' main complaints in the CAHR Report survey (2005).

In vitro fertilisation (IVF) is the most common form of treatment in Ireland, closely followed by intra uterine insemination (IUI) (WHC, 2009). An average cost for one IVF cycle is in the region of €4,000⁴ and for IUI is €800. Using donor sperm usually adds between €300 and €800 to the overall cost, while using egg donation is considerably more expensive costing between €5,000 and €12,000. Moreover, fertility drugs, which are commonly used with these procedures, can cost in the region of €2,000-3,000 depending on how a woman responds to treatment⁵. Additional costs in terms of initial consultations/ investigations, blood tests, and counselling fees are also common and can be substantial.

Finally, it should be noted that information on fertility clinics and their policies is not always easily accessible. Whether this is due to a fear of negative attention from those who oppose their services, the lack of an overseeing and regulating body, or some other reason, it is hard to assess. This difficulty further illuminates the need for openly available information and the key role played by voluntary support groups at the moment in assisting couples who are embarking on fertility investigations.

3.1.1 Regulation of services

Ireland has no official body or legislation for the regulation and licensing of clinics offering IVF or other ART, despite their presence in the country since the late 1980s (Cotter, 2009). The only guidance available to physicians practising in this area are the Medical Council's Ethical Guidelines (2004). No guidelines are available to other health professionals operating in this field, such as embryologists or counsellors, or in relation to other aspects of the management of fertility clinics, such as access, cost or liaison with follow-up care in relation to both successful and unsuccessful treatment. To address this lack of regulation, the Commission on Assisted Human Reproduction was established in 2000 and published its report in 2005.

³ This treatment is based on a detailed study of events occurring during ovulation and throughout the menstrual cycle, and by informing couples about their fertility and how to monitor their own fertility cycles. The aim of NaPro Technology is to allow conception through natural intercourse (WHC, 2009).

⁴ These prices are based on personal communications for eight of the ten Irish clinics during the summer months in 2009. The remainder did not respond to our inquiries.

⁵ Personal communication with Helen Browne, Chairperson, NISIG, 23rd July 2009.

Its key recommendation was the need to set up a robust infrastructure for the regulation and monitoring of ART services in Ireland, with corollaries to cover the various aspects of these objectives (CAHR, 2005). Regulation is desirable for a number reasons. It would help to curb any commercialisation of ART services, which are all privately run. It would enable the implementation of best practice guidelines for patient care and supply people using these services with an overseeing body to whom they could refer queries and complaints. Finally, it would support the gathering and publication of relevant statistics in terms of service users, and their outcomes to better inform service provision and policy in this area.

3.2 Psychological and Emotional Repercussions of Infertility Treatments

The greatest risk attached to IVF is its relatively low chance of success (Deech and Smajdor, 2007). Chances of a successful pregnancy following IVF in Ireland are approximately 20-25 per cent and this success rate is generally in line with international data (WHC, 2009). Nevertheless, couples embarking on an IVF programme are often very optimistic and have unrealistic expectations (Peddie *et al.*, 2005). The increased availability and perceived effectiveness of reproductive technologies may lead to even greater psychological and social consequences for the couple if their attempt(s) to conceive are unsuccessful (Hardy and Makuch, 2002; Haynes and Miller, 2003). Research shows that when ART are available, couples experiencing fertility problems feel compelled to try them, even if this means prolonging their distress and uncertainty in relation to their chances of procreation (Tymstra, 1989; Franklin, 1997; Deech and Smajdor, 2007). In spite of this, most couples do not regret having tried ART and feel that having tried this option makes it easier to come to terms with their biological childlessness (Hammarberg *et al.*, 2001; Sydsjö *et al.*, 2005). Anecdotal evidence also indicates that this is the case for Irish couples⁶.

One of the key challenges of research on the effects of infertility treatment is the ability to differentiate between the impact of infertility per se and that of its treatment (Greil, 1997; De Liz and Strauss, 2005; de Klerk *et al.*, 2006). This is mainly due to the limited information available on the experiences of those women and men who do not seek treatment, again pointing at the need to redirect some of the research in this field. Stress during treatment has been described as multi-dimensional (Verhaak *et al.*, 2007), originating from three different aspects of the experience:

- Chronic stress caused by the threat of infertility and the loss of hope;
- Stress from the prospect of treatment itself; and
- The stress of the actual participation in the treatment with its daily injections, scans and invasive procedures (de Klerk *et al.*, 2006; Lintsen *et al.*, 2009)

⁶ Personal Communication with Helen Browne, Chairperson, NISIG, 29th January 2009.

3.2.1 Implications of Treatment

While some women will have some negative physical side effects, such as pain, fatigue, headaches, nausea, weight gain, irritability, and menopausal symptoms (Cosineau and Domar, 2007; Peterson *et al.*, 2007)⁷, there is consensus among research participants that the emotional and psychological impact of treatment is more difficult to cope with than common physical repercussions (Verhaak *et al.*, 2005; Cosineau and Domar, 2007; Redshaw *et al.*, 2007). Most fertility patients also expect that addressing the psychological and social aspects of subfertility would be part of the overall treatment, but they are usually disappointed in this regard (Schmidt *et al.*, 2003; Schmidt, 2006; Cosineau and Domar, 2007). For this reason, many researchers in this field have advocated for the need to ensure that psychological supports are fully integrated into services and that they are available to patients throughout the treatment as needed.

Engagement with IVF often causes an increase in anxiety and stress levels (Schmidt *et al.*, 2003). Again, these symptoms can frequently be the side effects of hormonally-induced ovarian suppression (Eugster and Vingerhoets, 1999; Burns, 2007; WHC, 2009). However, they are also partly caused by the stress inherent to the strict regime of medication and appointment visits necessary to facilitate the process. Finally, increased anxiety is also linked to the fact that for many couples IVF represents the 'end of the line' (Shaw *et al.*, 1988 cited in de Klerk *et al.*, 2006) and these are likely to have already experienced extensive and emotionally challenging diagnosis and/or treatment processes. For these reasons, relationship strain often also increases during treatment (Leiblum *et al.*, 1998).

A number of studies have identified the most stressful times of treatment as: egg retrieval, the 16-day wait for the pregnancy test, a negative pregnancy testing day, after a miscarriage, and the wait between attempts (Eugster and Vingerhoets, 1999; Fekkes *et al.*, 2003). Therefore, it is critical that psychological support is made available and encouraged at these times for those who wish to avail of it. The need for psychological support is also crucial, given that studies have found a link between distress and pregnancy rates (Williams *et al.*, 2007). While the evidence is inconclusive, some research demonstrates that women with lower distress levels are more likely to conceive (Hammarberg *et al.*, 2001; Rajkhowa *et al.*, 2006; Verhaak *et al.*, 2007).

Many authors have described the all-consuming nature of treatment for women, who, because of their biological role, are also the ones that have to attend for all appointments, sometime on a daily basis. In addition to this draining and time-consuming aspect of the treatment for women, many couples also experience an existential 'limbo' (Sandelowski, 1993; Franklin, 1997; Boivin and Schmidt, 2005; De Liz and Strauss, 2005; Cosineau and Domar,

⁷ For a full review, see WHC, 2009

2007). Because so much of their future life is invested in and dependent on the result of treatment, many avoid making decisions in relation to many other aspects of their lives, such as career or education, property, or even planning holidays and social activities. Distress also seems to be related to the duration of treatment and the number of IVF cycles (Bergart, 2000; Cosineau and Domar, 2007).

When treatment is successful, anxiety and depression rates tend to return to normal levels. Studies comparing successful and unsuccessful couples clearly show that IVF treatment that results in parenthood has many benefits (De Liz and Strauss, 2005; Peddie *et al.*, 2005; Rajkhowa *et al.*, 2006; de Klerk *et al.*, 2007). Section 4.2 is dedicated to pregnancy and parenthood after successful IVF treatment.

3.2.2 Implications of Unsuccessful Treatment

Unsuccessful treatment is strongly associated with depression, anxiety, anger, helplessness, increased marital relationship tensions, grief and isolation (Leiblum *et al.*, 1998; Hammarberg *et al.*, 2001; Monach, 2005; Burns, 2007; Verhaak *et al.*, 2007; Lund *et al.*, 2009). Six months after unsuccessful treatment, approximately 20% of the women in a Dutch study showed subclinical forms of anxiety and/or depression (Verhaak *et al.*, 2005). A more recent Danish study reported that 14.8% of the women in unsuccessful treatment developed severe depressive symptoms at 1-year follow-up (Lund *et al.*, 2009).

An important recent finding is that a milder approach to IVF (short and milder ovarian stimulation with single embryo transfer) is associated with fewer symptoms of depression after overall treatment failure than standard IVF (de Klerk *et al.*, 2006; de Klerk *et al.*, 2007). Considering the significant negative psychological impact of IVF, it is important that clinicians make patients aware of their various options and point out their possible effects⁸.

One of the factors that appears to aggravate the effects of fertility treatment is the lack of a clear end point. Many couples report that while there is a clear path towards IVF, from less to more invasive treatments, there is no clear path out of IVF (Bergart, 2000; Throsby, 2004; Verhaak *et al.*, 2007). Research shows that the most commonly given reason for ending treatment is psychological distress, while finances and medical reasons are usually secondary considerations (Fekkes *et al.*, 2003; Throsby, 2004; Rajkhowa *et al.*, 2006). Some couples never make a conscious decision to stop 'trying' but are prevented from doing so by the emotional toll that treatment exacts, and lack of finances. This points to the need for including a plan for the end of treatment in consultations with fertility patients (Cosineau and Domar, 2007).

⁸ The implications and effectiveness of single embryo transfer (SET) are comprehensively addressed in the biomedical review of evidence (WHC, 2009) and will also be touched upon in the section on Multiple Births further on this report.

Another important consideration is the difference between short-term and long-term effects of treatment (Verhaak *et al.*, 2007; Klock, 2008). Studies show that most women adjust well to unsuccessful treatment, though a considerable group (~15%) experience clinical levels of anxiety and/or depression (Leiblum *et al.*, 1998; Verhaak *et al.*, 2007; Lund *et al.*, 2009). Relationship strain is also associated with the active phase of treatment, particularly if it is extended, and especially for those couples who are unsuccessful. But it recedes to 'normal' following the end of treatment (Leiblum *et al.*, 1998). For some couples even unsuccessful treatment has a positive impact on their relationship due to their having shared and survived a crisis in their lives (Hammarberg *et al.*, 2001; Repokari *et al.*, 2007).

It is estimated that it takes a minimum of two to three years to recover from treatment (Schmidt, 2006; Verhaak *et al.*, 2007). However, many writers have also commented on how the experience of infertility has long lasting effects on a couple's view of themselves and their world, even with the occurrence of a successful pregnancy or adoption (Leiblum *et al.*, 1998; Sarasohn Glazer, 1998; Verhaak *et al.*, 2005). Research has also found that focusing on new life goals was an effective strategy to recover from treatment and come to terms with childlessness (Throsby, 2004; Redshaw *et al.*, 2007). Adoption was also found have a positive effect on people's lives following IVF failure (Peddie *et al.*, 2005). The fact that people adjusted well to the inability to achieve biological parenthood should be communicated to infertility patients, as it might give them the opportunity to pursue other strategies or focus on other life goals earlier.

3.3 Key Issues

3.3.1 Information

As we have seen, many people have unrealistic expectations of their chances of success. Access to accurate and up to date information on success rates is therefore essential. In Ireland, there is no regulatory body for fertility clinics and therefore the data released by them is not monitored or evaluated for accuracy. Moreover, success rates in relation to the various treatments maybe confusing for the lay population as they are reported in clinical language and there is no standard format that allows for comparison between clinics.

A review of information provided in fertility clinics in The Netherlands found that information available to patients was poor and in need of improvement (Mourad *et al.*, 2009). A similar review of information provision in a Scottish clinic also found that patients were also dissatisfied with it (Porter and Bhattacharya, 2008). This is notwithstanding the existence of a regulatory authority in both of those countries. It is therefore reasonable to conclude that information provision might also be an issue in Ireland. In fact, the lack of sufficient factual information was one of the main complaints of NISIG members (CAHR, 2005). Information on

the physical risks and psychological repercussions involved in treatment should be available so that people can make informed decisions about their chances and whether fertility treatment is the best option for them. The same Dutch study found that infertile couples rated information provision as one of the most important aspects of good clinical care.

3.3.2 Psychosocial Support

As the review illustrates, infertility treatment can extract a heavy psychological toll for which patients are often unprepared. Fertility patients have expressed a need for more emotional advice and support, and for professional psychosocial services (Schmidt *et al.*, 2003; Schmidt, 2006). Members of NISIG included the relative lack of counselling available as one of their main complaints in relation to treatment services and 75% of couples who received counselling found it beneficial (CAHR, 2005). While not all patients will require psychosocial supports, it is vital they are available for those who do.

Two reviews of psychosocial interventions found that they are effective in improving the well-being of participating couples (Boivin, 2003; Wischmann, 2008). Boivin (2003) found that group interventions which emphasised education and skills training (e.g. relaxation techniques) were significantly more effective in producing positive change than counselling which emphasised emotional expression and support and/or discussion about thoughts and feelings related to infertility. Wischmann (2008) found counselling and support groups to be the most efficient psychosocial interventions. It is argued that the beneficial aspect of support groups stems from being able to share experiences related to infertility, realising that problems are common and negative reactions to it normal, and being able to share information and ideas for coping (Bergart, 2000; Boivin, 2003; Klock, 2008).

Reviews of best practice in psychosocial supports for fertility patients have suggested that counselling should take place before infertility treatment to provide patients with the opportunities to learn the skills to cope with the infertility and the associated medical procedures (Fekkes *et al.*, 2003). Research also suggests that it is just as important to ensure that psychological support is available throughout treatment, especially at those times that have been identified as most stressful, such as egg retrieval or waiting for a pregnancy result (Verhaak *et al.*, 2007).

Another important provision is that psychotherapeutic interventions continue after unsuccessful treatment while patients come to terms with involuntary childlessness (Redshaw *et al.*, 2007). The need to include the probability of failure and steps towards preparing for it, such as considering other family formation options, e.g. gamete donation, adoption, fostering, or accepting childlessness and moving toward new life goals is also an important element of proper psychological support (Hammarberg *et al.*, 2001).

Many people nowadays use the Internet to gather information and access support groups, and women diagnosed with infertility have been found to be active users (Okamura *et al.*, 2002). In fact, it appears that more than half of fertility patients go online to gather fertility-treatment information (Cosineau and Domar, 2007). However, content on the Internet on this subject is often of poor standard (Okamura *et al.*, 2002), highlighting the need for clinics to direct their patients to reliable sources. A review of an evidence-based eHealth programme for women experiencing infertility suggested that a web-based patient education programme can have beneficial effects in several psychological domains and may be a cost effective resource for fertility practices (Cosineau *et al.*, 2008).

All evidence points to the fact that good practice in fertility clinics encompasses more than medical care (Boivin *et al.*, 2001). Feedback from patients on their experiences of treatment provides suggestions for improvements (Schmidt, 1998). These are listed below:

- patients only wish to interact with few staff members;
- the treatment should follow a plan which is known to both the doctor and the couple;
- treatment should proceed without waiting times;
- staff should actively invite the male partners to participate in the investigations and in the treatment process;
- staff should show empathy and the clinic should offer counselling about the psychological and sexual consequences of infertility and treatment;
- staff should have knowledge about alternative ways of becoming parents (adoption and fostering); and
- staff should invite the couple to discuss alternatives to medical fertility treatment.

A more holistic approach to patient care is believed to improve health outcomes, increase patient and team satisfaction, reduce negative psychosocial reactions and help patients better come to terms with their experience (Boivin *et al.*, 2001).

Four: Pregnancy and Parenthood

4.1 Pregnancy

The most positive outcome of infertility treatment is the birth of a longed for baby. While success rates are still relatively low, a quarter of couples will succeed in achieving parenthood (WHC, 2009). However, even when conception occurs and the pregnancy progresses well, the experience can be very different to that of those unaffected by fertility problems. Two systematic reviews have found that couples who achieve pregnancy after treatment, especially when that treatment is prolonged, experience higher anxiety levels in relation to the pregnancy (Eugster and Vingerhoets, 1999; Hammarberg *et al.*, 2008). This anxiety might be linked to evidence showing that a pregnancy following ART has a higher risk of complications than one following natural conception (WHC, 2009, (Ludwig, 2002). However, it has been argued that it is more likely to be related to the fact that infertility causes people to anticipate loss and to consider their pregnancy as 'tentative' (Sarasohn Glazer, 1998; Redshaw *et al.*, 2007).

Another difficult and unusual aspect of pregnancy for subfertile couples is that it can often be a lonely experience. Couples pregnant after ART feel different from their fertile peers but are reluctant to share their excitement or worries with their infertile friends or support group members for fear of hurting them and appearing insensitive (Sarasohn Glazer, 1998).

Many also often worry about the possibility of negative health consequences from ART on their children, and this worry is not wholly unjustified. It has been found that compared with non-assisted singleton pregnancies, singleton pregnancies from ART have a significantly worse perinatal outcome (Helmerhorst *et al.*, 2004). The most up to date and comprehensive review of the link between ART and birth defects, carried out in the USA, also shows that some birth defects, especially digestive tract abnormalities, cleft palate and heart problems, occur more often among infants conceived by ART than in those conceived naturally (Reefhuis *et al.*, 2008). This increased rate has been linked with the parents' underlying infertility problem rather than ART treatment per se (Soini, 2006; Reefhuis *et al.*, 2008; Steel and Sutcliffe, 2009).

4.2 Parenthood

While concerns have been expressed about the effect of ART on parenting and child development, research shows that ART parents are generally well adjusted and have a good relationship with their children (Golombok, 2001). Moreover, a European-wide comparative study indicated that when differences are found, these mainly reflected a more positive functioning among ART families than adoptive and naturally conceived families (Golombok *et al.*, 2002). Some studies, though, have documented higher levels of anxiety about parenting and lower postnatal self-confidence in ART mothers (Golombok, 2001; Golombok *et al.*, 2002; Ellison *et al.*, 2005; Hammarberg *et al.*, 2008). It has been argued that in pregnancy after ART, parenthood might be idealised and this might then hinder the adjustment to the reality of

looking after a baby and the development of a confident parental identity (Hammarberg *et al.*, 2008). However, mothers of children conceived by ART have been found to express greater warmth towards their child, and to be more emotionally involved than naturally conceiving mothers (Eugster and Vingerhoets, 1999; Golombok, 2001; Golombok *et al.*, 2002). ART fathers have also been found to report less parenting distress and to interact with their child more than their naturally conceiving counterparts (Golombok *et al.*, 2002). Both positive and negative differences seem to be relatively short-lived, and to disappear by the time the child reaches adolescence (Golombok *et al.*, 2002; Repokari *et al.*, 2005).

Another feature of ART parenthood is that many parents feel under pressure to try for a second pregnancy, to achieve that 'complete' family, shortly after the birth of their first child (Sarasohn Glazer, 1998; Throsby, 2004). This pressure stems from the knowledge that attempts to achieve a second pregnancy might also be prolonged and negatively influenced by increasing maternal age. This situation further increases levels of anxiety and also impacts on the couple's ability to enjoy their firstborn.

With respect to children themselves, a recent follow-up of the European Study of Assisted Reproduction Families found that adolescents who had been conceived by IVF were generally functioning well and had no negative feelings about their conception (Golombok *et al.*, 2009). Moreover, they had a good relationship with their parents that did not differ from those of adopted and natural conception adolescents. In fact, there is no evidence to suggest that children conceived by ART are at risk of impaired cognitive or socio-emotional development (Golombok, 2001; Golombok *et al.*, 2002; Golombok *et al.*, 2007). Unfortunately, the outcomes for ART children born as part of a multiple birth are not as clear, as described below.

4.2.1 Multiple Births

Many couples undergoing fertility treatment express the wish for a twin pregnancy to achieve an 'instant family' (Child *et al.*, 2004; Baor and Blickstein, 2005; Olivennes *et al.*, 2005; Vilska *et al.*, 2009). This wish seems to be positively correlated to the duration of infertility and the number of previous ART attempts (Child *et al.*, 2004; Baor and Blickstein, 2005).

However, while they might seem desirable from a social point of view, multiple pregnancies are linked to a significant increase in mortality and morbidity for both the mother and babies. The maternal risks associated with a multiple pregnancy include increased risk of miscarriage, pregnancy induced high blood pressure, anaemia, pre-eclampsia⁹, gestational diabetes, increased chance of hospitalisation before the birth, caesarean section and post-partum haemorrhage¹⁰ (WHC, 2009). Half of twin babies and 90% of triplets are born prematurely with

⁹ A condition during pregnancy that has symptoms of high blood pressure, fluid retention and protein in the urine. The condition may be mild or serious.

¹⁰ Excessive bleeding after birth.

low birth weight. When compared with singleton births, twins are five times more likely to die within the first week of life (triplets are nine times as likely), and twins are 4 times as likely to have cerebral palsy (triplets are 18 times as likely) (WHC, 2009).

Apart from the physical risks, most ART patients do not fully appreciate the additional practical, financial and emotional stresses that often result from having multiples. While every birth brings a certain amount of upheaval, stress and exhaustion, studies show that the birth of twins can result in particularly high levels of stress and difficulties in family relationships (Baor and Blickstein, 2005; Olivennes *et al.*, 2005; Golombok *et al.*, 2007; Vilska *et al.*, 2009). Isolation among mothers of multiples is also common due to the logistical challenges involved in transporting two or more infants. Financial stress also plays a role, as the financial burden of raising multiples is higher than that of raising the same number of singletons. It is not therefore surprising that studies have found mothers of multiples to be particularly vulnerable to depression (Klock, 2004; Baor and Blickstein, 2005; Sheard *et al.*, 2007; Choi *et al.*, 2009).

In addition, studies have shown that parents of multiples often feel guilty for not giving enough attention to each child (Baor and Blickstein, 2005; Golombok *et al.*, 2007), or for not enjoying their newfound parenthood after years of trying (Klock, 2004). This guilt is compounded by the notion that the situation is 'self-inflicted' and therefore they should not be complaining or asking for help from family and friends (Klock, 2004; Ellison *et al.*, 2005; Strauss *et al.*, 2008). Research shows that parents of naturally conceived twins experience lower rates of parenting stress and higher rates of parental satisfaction than those of ART twins, indicating that the 'self-inflicted' nature of the multiplicity and/or the emotionally draining experience of the preceding infertility treatment also play a part in their ability to cope with multiple births (Ellison *et al.*, 2005; Strauss *et al.*, 2008).

The issue of stigma is also one that must be mentioned. Because of the link between ART and multiple births, popularised in the media, a multiple birth often exposes couples to unwanted speculation and intrusive questions about their fertility status and their children's conception, compounding existing levels of stress and emphasising feelings of isolation (Ellison *et al.*, 2005).

In relation to the children themselves, no difference in the level of emotional or behavioural problems between twins and singletons born after ART has been found (Olivennes *et al.*, 2005). Twins show significantly lower levels of cognitive functioning, however, especially in relation to language development, which is probably linked to the problem of having to constantly share the attention of their carers (Denton and Bryan, 2002; Olivennes *et al.*, 2005).

The increase in the rate of live multiple births over the last number of years by 27% (from 1,463 in 1999 to 1,859 in 2005) attests to the impact of fertility treatments in this area (DoHC and ESRI, 2008). In fact, in 2005, 25.1% of all deliveries after IVF and ICSI in Ireland were multiple births (Nyboe Andersen *et al.*, 2009) in contrast with a live birth rate of 3% for naturally conceived multiples (DoHC and ESRI, 2008).

4.2.2 Gamete Donation

While embryo donation is allowed under the Ethical Guidelines of the Medical Council (2004), no data is available on its prevalence, and it is presumed to be an infrequent occurrence because of the ethical and religious views on the status of the embryo in Ireland and the lack of regulation in this area. Therefore, this section will focus on gamete donation, primarily covering evidence on the implications of sperm donation as the vast majority of the research has been carried out in this field. This is because sperm donation is both an older and a more common process than egg donation (Golombok, 2001; WHC, 2009). However, it is likely that similar issues would be relevant to all three forms of donation as they share crucial characteristics: the break of the genetic link with one or both of the social parents, the impact on the resulting family and child(ren)'s identity, and the potential for stigma and criticism based on cultural and religious beliefs (Golombok, 2001; ESHRE Task Force on Ethics and Law, 2002).

Research shows that families formed through donor insemination function well and are characterised by stable and warm relationships (Golombok, 2001; Golombok *et al.*, 2002; Golombok *et al.*, 2005). The lack of a genetic link does not interfere with the development of a positive relationship between fathers and children, suggesting that genetic ties are less important for family functioning than a strong desire for parenthood. Donation also does not appear to have any negative effects on children's psychological wellbeing (Golombok, 2001; Golombok *et al.*, 2002; Golombok *et al.*, 2005).

The two contentious issues in relation to donation are the donor's right to anonymity and the child's right to know his/her genetic origin. Many countries have now passed legislation to reduce the donor's right to anonymity and provide access to information on the donor in different circumstances and upon the reaching of a certain age by his genetic child. The reasons for concern about secrecy and the lack of access to genetic information originates in the findings of research on adoption. These showed that adopted children benefit from knowledge about their biological parents, and that when they are not given such information they may become confused about their identity and at risk of emotional problems (Golombok, 2001; Golombok *et al.*, 2002).

Despite this evidence, rates of intention to disclose and actual disclosure remain generally quite low, at around 50% and 10% respectively (Gottlieb *et al.*, 2000; Golombok *et al.*, 2002; Lycett *et al.*, 2005; Johnson and Kane, 2007). This is the case even in those countries where legislation revoking donor anonymity and guaranteeing information on his identity is in place. Although, a recent small-scale study in Sweden found a higher disclosure rate of 61% (Lalos *et al.*, 2007), pointing to a possible positive effect on disclosure rates by the enactment of legislation in that country. Unfortunately legislative regulation often also leads to a drop in donation rates (Jones and Coher, 2007). While there are no actual disclosure rates available in Ireland, a survey of NISIG members indicated that 25% of them had decided to tell their children about their conception, 20% had decided not to and 50% were undecided (CAHR, 2005).

The main reasons couples give for not wishing to disclose are fear of stigma for both the father and the child, the inability to access genetic information on the donor, and insecurities about how to disclose to the child (Daniels *et al.*, 1995; Lycett *et al.*, 2005; Freeman *et al.*, 2009). The risk of accidental disclosure, however, may be considerable as most parents through donor insemination tell a friend or family member about the child's donor conception (Lycett *et al.*, 2005; Lalos *et al.*, 2007). In addition, improved genetic technology increases the possibility of discovery through medical tests and procedures (Golombok *et al.*, 2002; Lycett *et al.*, 2005).

Another important social consideration is the fact that gamete donation also technically allows those who might be referred to as 'socially infertile' (Britt, 2001 in Throsby, 2004), such as gay and lesbian couples, and single men and women, to achieve parenthood. However, often discrimination in accessing services prevents them from availing themselves of this opportunity, as we will see in section 6.2 of the report.

4.3 Key Issues

4.3.1 Information and Support

From the review above, it is clear that couples who are affected by fertility problems continue to require information and support during pregnancy and into parenthood. As we have seen, their experience differs from those who conceive naturally and that might also have repercussions on their wellbeing and parenting experience.

Information is also required in relation to any potential risk linked to the resulting child. Sufficient evidence is now available to highlight the slight increase in the likelihood of birth defects while at the same time providing reassurance of the lack of negative consequences in terms of cognitive and socio-emotional development in singletons born following ART.

4.3.2 Multiple Births

It can be difficult for couples to make a decision about the number of embryos to be transferred, when they may be under emotional stress in their long and painful quest for a baby (Denton and Bryan, 2002). Therefore, it is important that clinicians promote a single embryo transfer policy for good-prognosis patients and reassure them of its effectiveness. Recent reviews of single embryo transfer (SET) have shown that effectiveness is not undermined if good-prognosis patients are targeted and if effective embryo freezing programmes are available, so that patients might undergo a number of embryo transfers from one IVF cycle (Braude, 2006; Veleva *et al.*, 2009)¹¹. In Ireland, single embryo transfer (SET) accounts for only 8.7% of all transfers, which is much lower than the European average (20.0%) (Nyboe Andersen *et al.*, 2009). On the other hand, the rate of double embryo transfers is considerably higher than its European equivalent (79.8% vs 56.1%) (*ibid.*). However, far fewer transfers of three or more embryos take place here (11.9% vs 23.8%). Not surprisingly, the birth rate of multiples following ART in Ireland is higher than the European average (25.1% vs 21.8%) (*ibid.*).

While the older average age of women undergoing ART in Ireland might partly explain the high double embryo transfer rate (WHC, 2009), it may also be influenced by other factors. One of the reasons identified for the high incidence of multiple births following ART is the commercial nature of the clinics and the cost-effectiveness of the treatment (ESHRE Task Force on Ethics and Law, 2003). Competition between clinics creates pressure to maximise pregnancy rates. In order to overcome the competing interests of clinics and patients, it has been recommended that the reporting system for results is harmonised and emphasis is put on the rate of singleton pregnancies as a success and that of multiple births as a complication (ESHRE Task Force on Ethics and Law, 2003; Braude, 2006).

As we have seen, undergoing fertility treatment is a costly experience for couples, and embryo freezing, or cryopreservation, usually entails an additional fee. It has been found that financial pressure is often one of the reasons patients ask for multiple embryo transfer, i.e. to maximise the chances of conception in a single cycle (ESHRE Task Force on Ethics and Law, 2003). There is evidence that the incidence of multiple pregnancies is lower in countries that provide public subsidies for ART (ESHRE Task Force on Ethics and Law, 2003; RCOG, 2008). Therefore, financial support should be available in order to ensure that discrimination in this aspect of ART is minimised. The availability of financial support for cryopreservation would also lessen the pressure many couples feel to undergo treatment again shortly after the birth of their first child, enabling them to recover physically and emotionally, and better enjoy their experience as new parents¹². The importance of addressing the financial side of ART is further addressed in section 6.1.

¹¹ For a full review of these issues, see this report's companion publication (WHC, 2009).

¹² Encouragingly, a recent systematic review has found that cryopreservation does not seem to have a negative impact on neonatal outcomes (Wennerholm *et al.*, 2009).

Finally, for families of twins and higher order multiples, continuity of care in terms of counselling and support services should be provided to ameliorate the psychosocial risks related to this still common treatment outcome.

4.3.3 Gamete Donation

Parenthood following gamete donation also poses some additional challenges, as we have seen. Lessons learnt from the research on adoptees point to the need to avoid secrecy and provide the child with information on his/her identity. Since, this knowledge is usually linked with the desire to know more about the donor, the use of identifiable donors is now perceived as a positive development and legislation to support this is now in place in various countries.

In term of disclosure to the resulting child(ren), evidence shows that age is an important factor both in terms of its likely occurrence and impact (Golombok *et al.*, 2002; Freeman *et al.*, 2009; Jadva *et al.*, 2009). It is believed that the process of informing a child about donor insemination is easiest if it is begun when the child is young, and if increasing amounts of information are added as the child ages (Gottlieb *et al.*, 2000). As children grow older it becomes more difficult for parents to tell them that they were conceived using donor sperm (Gottlieb *et al.*, 2000; Golombok, 2001; Lalos *et al.*, 2007). One study showed that some people who found out about their conception by donor insemination in adulthood, often in negative circumstances such as parental divorce or death, felt hostile towards their parents and mistrustful of them (Turner and Coyle, 2000). Another recent study supports this claim indicating that those told later in life report reported more negative feelings regarding donor conception than those told earlier (Jadva *et al.*, 2009). Moreover, parents who shared the information with their teenage or adult donor-conceived child have revealed that keeping donor conception a secret was both burdensome and a pressure (Johnson and Kane, 2007; Daniels *et al.*, 2009). Invariably these parents said that they wished they had shared the information with their children earlier.

In a study of school-aged children, their reaction to disclosure included disinterest, curiosity, interest in the story, and a desire to know more about the donor (Lycett *et al.*, 2005). However, no negative reactions were found. This was also the case in a European-wide study that included children during the transition to adolescence (Golombok *et al.*, 2002). The same study showed that families where the parents had disclosed the circumstances of the child's birth experienced less conflict and, contrary to the fears expressed by the parents, disclosure may have even had a beneficial effect on the quality of parent-child relationship (Golombok *et al.*, 2002). Parents who had told their children generally described the telling experience as a positive one (Lycett *et al.*, 2005; Lalos *et al.*, 2007) and did not regret doing so (Johnson and Kane, 2007). Support and counselling should be available to couples engaging in this process both pre- and post-treatment in order to assist them in negotiating this challenging process.

Many couples also decide not to disclose because of fear of criticism and discrimination towards them but especially towards their child (Golombok, 2001). In this aspect of infertility, just as in all the others, social and cultural expectations place a heavy burden on those who cannot achieve a genetic link with their child. Public debate and information for the public via formal education, awareness campaigns and the media are therefore vital to dispel myths and provide evidence-based findings of the good quality of relationships in families formed through gamete donation. In fact, positive cultural attitudes towards gamete donation have been deemed to be more effective than legislation alone to influence disclosure rates (Golombok *et al.*, 2005).

Five: Gender, Infertility and its Treatments

5.1 Gender and infertility

While the devastating effects of infertility are felt by both women and men, the evidence points to a much more negative effect on women's lives (Greil, 1997; Hardy and Makuch, 2002; Schmidt *et al.*, 2003; Cosineau and Domar, 2007; Repokari *et al.*, 2007; Peterson *et al.*, 2009). Compared with men, women in infertile couples have lower self-esteem, are more depressed, report lower life-satisfaction, are more likely to blame themselves for their infertility, and are more likely to regard childlessness as being unacceptable (Greil, 1997; Hardy and Makuch, 2002; Boivin and Schmidt, 2005; Peterson *et al.*, 2006; Cosineau and Domar, 2007; Peterson *et al.*, 2007; Slade *et al.*, 2007). They also experience more social consequences and feel a higher level of stigma (Greil, 1997; Slade *et al.*, 2007). Infertility has been described as a "developmental crisis for a woman, disrupting her identity, her relationships and her sense of meaning" (Bergart, 2000: 45).

The reasons for women's more negative experience are many, but are all linked to women's biological and social role as mothers and how this role defines their identity much more in society than men's roles as fathers (Greil, 1997; Fathalla, 2002; Peterson *et al.*, 2007; Klock, 2008). The pervasiveness of a woman's role as mother is effectively described by Wirtberg (1992, cited in Schmidt *et al.*, 2005) who found that infertility and childlessness affected women in all areas of life – there was no context where relief could be obtained. In contrast, work and spare-time activities were, for most men, 'pain-free' zones (Schmidt *et al.*, 2005). Greil and his associates have argued that the effect of infertility on women is more 'direct' while for men its effect is mediated through their relationship with their partners (1997). They also poignantly noted that the fact that gender roles are more important than who has the reproductive impairment shows that infertility is best understood as a socially constructed process rather than merely a physical condition.

In many ways, men's responses to infertility are similar to women's (Peterson *et al.*, 2006; Peterson *et al.*, 2007). They also experience guilt, shame, low self-esteem, anger, isolation, loss and personal failure (Peterson *et al.*, 2007). The inability to father a child may affect a man's identity and lead him to question his masculinity. This is especially the case in relation to male factor infertility (Hardy and Makuch, 2002; Throsby, 2004; Cosineau and Domar, 2007). Two recent studies have shown that unsuccessful treatment also has a devastating effect on men (Holter *et al.*, 2006; Peronace *et al.*, 2007).

However, men's experiences are often either under-represented or invisible in research carried out in this field (Greil, 1997; Throsby, 2004; Cosineau and Domar, 2007). It has also been suggested that men's tendency to suppress their emotions in an effort to support their partner may result in the under-reporting of actual levels of infertility-related distress among them (Cosineau and Domar, 2007). Men experiencing infertility have been found to be less likely than their partners to communicate about their emotional pain, thus isolating themselves

from their friends and family (Peterson *et al.*, 2007). Nevertheless, in general, for men fertility-related stress appears to be relatively more contained, not to influence more generic functioning and not to differ from other forms of life stress (Verhaak *et al.*, 2005; Peterson *et al.*, 2006; Cosineau and Domar, 2007; Slade *et al.*, 2007).

5.2 Gender and Treatment

One of the reasons why women experience more stress during treatment is certainly linked to the fact that they are the 'patient' regardless of whose infertility is impaired. It is most often the women who undergo the bulk of invasive procedures, are responsible for daily monitoring of their menstrual cycles, and experience disruption in their schedules to accommodate rigid treatment regimens. Because of this practical and psychological impact on their lives, as well as the more complex social reasons illustrated earlier, it is women who disproportionately carry the burden of infertility treatment (Fathalla, 2002; Cook *et al.*, 2003; Throsby, 2004; Cosineau and Domar, 2007; Deech and Smajdor, 2007). This situation further emphasises their role and identity as procreators and makes it more difficult to cope with the distress of infertility and unsuccessful treatment. For this reason, infertility treatment has been described as a double-edged sword for women which can bring hope but increases their burden at the same time (Ryan-Sheridan, 1994; WHC, 2002; Andres, 2006; Deech and Smajdor, 2007).

Apart from physical and emotional repercussions, treatment often has very significant practical implications for women. Because of its consuming and often debilitating nature, women have to plan their lives very carefully around it and feel unable to commit to other activities, such as holidays or social gatherings, while engaging with it. They may need considerable time off and choose to put their work or educational plans on hold. Research in this area shows that women felt that undergoing fertility treatment frequently negatively affected their careers and their finances (Woods *et al.*, 1991; Deech and Smajdor, 2007; Redshaw *et al.*, 2007). The potential negative effect on their careers has been found to be one of the reasons why women do not disclose their engagement with fertility treatment in their work environment (Finamore *et al.*, 2007).

It has been suggested that one of the reasons men do not appear as affected by infertility is because the achievement of fatherhood does not seem as vital to men's identity as motherhood is to women's (for example, see Fathalla, 2002). Research has shown that men engaging in fertility treatment are mainly partner-focused (Greil, 1997; Schmidt *et al.*, 2003; Peterson *et al.*, 2006). That is to say that women seek treatment for both themselves and their partners whereas men seek it mainly for their partner (Schmidt *et al.*, 2003). The extract below, while being anecdotal, vividly portrays how gender differences play themselves out in a couple's real lived experience of infertility treatment:

"For me [male partner] the long chronicles of test and experiment, trial and failure, hopes raised and dashed, had produced multiple disappointments but nothing like the depth of feeling Elizabeth suffered. Where I had only to be patient she had to be committed. Where I needed adaptability she needed resilience. It was enough if I was determined: she had to be endlessly brave...Her stresses inevitably meant that I had to curb the expression of my own: I felt I had to do all I could to avoid adding to her burdens".

(Higgins, 2003: 29)

The coping mechanisms of women and men when dealing with infertility treatment also seem to be affected by gender (Peterson *et al.*, 2009; Schmidt, 2009). Women tend to seek more social support, engage in positive re-evaluation, and resort to escapism, while men engage in more distancing, self-controlling and problem-solving coping mechanisms (Peterson *et al.*, 2006). Research shows that more women than men perceive psychosocial services within the fertility clinic setting as important (Schmidt *et al.*, 2003). Studies also show that when men do access psychosocial interventions, they also benefit from them but do so for different reasons than their partners (Boivin, 2003; Peterson *et al.*, 2006).

The majority of women found counselling

useful because of the sense of belonging and validation of their reactions, whereas men felt support groups were good because of the practical information and advice they received. Research analysing the nature of queries to infertility telephone helplines also shows this gender divide with men more likely to call with practical or medical queries compared to women, who generally sought emotional support. While no Irish research is available on the gender aspects of infertility and its treatment, anecdotal evidence supports the gender differences presented above¹³.

One final point to make about gender and treatment is that while research has focused on the effects of infertility treatment on women and, less often, men, popular discourse commonly ignores this aspect of treatment, focusing solely on the controversial issue of embryos (WHC, 2002). While this aspect is by no means unimportant, it is crucial that the lived experiences of couples undergoing these treatments are not ignored in the debates surrounding the moral and ethical nature of embryos and their potential uses.

¹³ Personal Communication with Helen Browne, Chairperson, NISIG, 29th January 2009.

5.3 Key Issues

5.3.1 Gender Roles

In terms of promoting the health and well-being of women, addressing cultural notions of women's identity as being inextricably linked with procreation would bring the most benefit to women experiencing fertility problems. For this purpose it is key to emphasise women's engagement and contribution in other aspects of society as well as to rebalance the public discourse around children towards a greater contribution by men in this sphere (Deech and Smajdor, 2007). While emphasising other aspects of women's identity and social roles would not necessarily alleviate the pain of not being able to have greatly desired children, it would help in imagining the possibility of a positive future and fulfilment without them (Throsby, 2004).

4.3.2 A couple-centred approach

Notwithstanding the recommendation above, many women will still desire motherhood and choose to undergo fertility treatment to achieve this goal. General recommendations in relation to how to improve services have already been dealt with in section 3. In terms of gender aspects, one of the key concerns is the need to take a couple-centred approach (Greil, 1997; Schmidt *et al.*, 2003; National Collaborating Centre for Women's and Child's Health, 2004; Schmidt, 2006; Klock, 2008), while at the same time giving due consideration to the specific needs of both parties involved. Research shows that women may require additional supports as they are disproportionately affected by both infertility itself and by its treatment. Such an approach will help to alleviate some of the burden of infertility treatment on women and also encourage men to become more involved in the process and to voice their own fears and concerns. A couple-centred approach is also the one preferred by most patients (Schmidt *et al.*, 2003).

Six: Access Issues

6.1 Financial Cost

The issue of access to infertility treatments is a contentious one in Ireland and worldwide (Fathalla, 2002; Benagiano *et al.*, 2006). It is well recognised that infertility treatment comes at considerable financial cost (Kelly *et al.*, 2006; Deech and Smajdor, 2007; Redshaw *et al.*, 2007; Klock, 2008). As we have seen, fertility clinics in Ireland are all private, and, while public patients do have some access to them, it is limited and at the clinics' discretion. Some financial assistance is provided by the State for ART patients. They can offset the cost of private treatment against their income tax liability¹⁴ and the cost of prescribed ART medicines is an allowable expense under the Drugs Payment Scheme¹⁵. However, health insurance companies have so far excluded infertility related treatments from their coverage, even when the infertility is linked to medical conditions, thus practically discriminating against people affected by them¹⁶. Therefore, cost is still prohibitive for a significant section of the Irish population, and many couples pursuing treatment stretch themselves to the limit of their budget (Kelly *et al.*, 2006). Many more are not able to access these treatments at all and this can be a source of great regret to them¹⁷. The cost of treatment has been found to further compound the stress of even those couples who can afford it (Cosineau and Domar, 2007).

Apart from the price of treatment, couples, and especially women, also often turn down career or educational opportunities to be able to focus solely on attaining biological parenthood, as seen earlier. Many women opt for part-time working arrangements or decide to give up work altogether as the energy, time commitment, physical and psychosocial repercussions of treatment can sometimes prevent them from engaging in other activities. Therefore infertility treatment often carries a high opportunity-cost in terms of future income, as well as income foregone in the short-term.

¹⁴ From January 2009, tax relief on medical and health expenses is at the standard rate of 20% (Citizen Information, 2009).

¹⁵ Under the Drugs Payment Scheme you can only pay a maximum of €100 a month for approved prescribed drugs and medicines (Citizen Information, 2009). However, since March 2009, the HSE has set a limit to the number of cycles of IVF or ICSI treatment where medication can be subsidised. Once patients have completed three cycles of IVF or ICSI, they will no longer be eligible under the Drug Payment Scheme for assistance with the cost of medication in any future treatment cycles.

¹⁶ Personal communication with Helen Browne, Chairperson, NISIG, 29th January 2009.

¹⁷ Personal communication with Helen Browne, Chairperson, NISIG, 29th January 2009.

6.2 Equality Issues

Assisted reproductive technologies have the potential to enable those who are 'socially infertile' (Britt, 2001, in Throsby, 2004), such as lesbians and gays, and single women and men, to become parents. Research to date has pointed to the equally positive development of 'less traditional' families formed through ART (Golombok, 2001; Golombok *et al.*, 2002).

An international review of services indicates that Irish clinics will see couples 'in a stable relationship' (Jones and Coher, 2007). The most recent edition of the Medical Council's Ethical Guidelines also refers to 'the couple' with previous requirement for married status having been removed (2004). From communications with Irish fertility clinics, it appears that some of them will only see married couples, some will see heterosexual couples in a long-term relationship, two will provide services to all those who wish to avail of them, including same-sex couples and single men and women. Another one will provide services to all of the above, apart from single men. However, members of NISIG who are in same sex relationships or single have experienced difficulties in accessing services appropriate to their needs in Ireland and often have to travel abroad for them¹⁸. So while access seems to be available to all who can afford it, significant barriers do persist for some groups of people.

On a positive note, geographical spread is relatively equitable with most major centres covered. However, many couples seem to prefer the anonymity of Dublin to a local unit (Kelly *et al.*, 2006), again pointing to the stigma of infertility. Nevertheless, as we have seen, the limited choices in service providers and distance from the clinic were some of NISIG members' main complaints in the CAHR Report survey (2005).

Because of the various difficulties in access mentioned above many Irish patients engage in 'medical tourism', travelling abroad to receive fertility treatment there. Anecdotal evidence points to the UK, Spain, and Belgium as being among the countries of choice for treatment. Countries of choice for treatments involving donor eggs include Spain, the Czech Republic and Greece¹⁹. The main concerns regarding this practice are the lack of quality assurance in relation to services offered abroad, as well as the possibility of missing critical information in any follow-up care.

¹⁸ Personal communication with Helen Browne, Chairperson, NISIG, 20th August 2009.

¹⁹ Personal communication with Helen Browne, Chairperson, NISIG, 30th July 2009.

6.3 Key Issues

Considering the physical and psychological burden of infertility, it is paramount that all those who wish to access treatment should be able to do so. Current services discriminate on financial grounds as well as other grounds covered by the Equality legislation. Studies have shown that when public funds are available, more couples tend to seek treatment (White *et al.*, 2006). Moreover, better clinical decisions are often made when coverage by the public health care system includes fertility treatments, for example in relation to embryo transfer (ESHRE Task Force on Ethics and Law, 2003). The Institute of Obstetricians and Gynaecologists has also recommended the public funding of assisted reproduction services (Institute of Obstetricians and Gynaecologists, 2006).

In terms of other types of discrimination, once again, the Women's Health Council reiterates its support for the recommendations of the CAHR and the implementation of the Equality Legislation by all fertility services.

Seven: Conclusions & Recommendations

This review aimed to highlight the fact that psycho-social issues are as relevant and often as crucial to fertility treatment as physical ones. Furthermore, the Women's Health Council wished to emphasise the fact that ART, while mostly engaging with biological factors, also interact with important social issues, such as cultural views on family formation and gender roles. In this regard, ART tend to reinforce existing gender roles and behaviours, often to the detriment of both women's and men's wellbeing.

As we have seen, fertility problems affect a considerable number of couples in Ireland and can have significant psycho-social repercussions. The treatment of subfertility can bring an additional psychological and emotional burden which is often not sufficiently addressed in clinical settings. Even when treatment is successful, resulting in the long wished for baby, challenges remain, especially in the case of multiple births and children conceived through gamete donation.

"There is an imbalance between the level of sophistication and the care given to every small detail of the technologies for assisted reproduction and the attention given the feelings, fears and anxieties of the infertile couple, the psycho-social consequences of infertility and of treatment failure, as well as the gender differences between the effects that these technologies have".

(Hardy and Makuch, 2002: 274)

In light of our findings, the Women's Health Council wishes to encourage a renewed impetus to address the issue of infertility and the challenges inherent in it from both individual and societal perspectives. Much can be done to alleviate the distress of couples affected by infertility, both in terms of our ability as a society to be mindful of its existence and repercussions, and by improving current service provision. More attention should also be given to its prevention and more research should be dedicated to finding its causes and cures rather than bypassing the problem through ART. Finally, it continues to be paramount

that the recommendations of the Commission on Assisted Human Reproduction be implemented as a matter of urgency. This step would go some way towards ensuring a robust legal and regulatory framework is in place to ease the minds of those having to navigate the uncharted waters that are ART in Ireland today.

7.1 Social Aspects

- Raising public awareness of fertility problems: their causes, repercussions and possible treatments.
- Dialogue on social repercussions of ART and gamete donation.
- Policies and appropriate supports to promote younger parenthood.

7.2 Support and Treatment

- Increased availability of information on treatments, including success rates and possible repercussions, and support groups.
- Increased attention to psycho-social issues during treatment.
- Adoption of a couple-centred approach.
- Legislation and regulation of ART, including the implementation of the Equality Legislation through service provision.

7.3 Research

- Increased emphasis on prevention and treatment of infertility.
- Increased emphasis on male infertility and its treatment.
- Research needed on psycho-social effects of ART in Ireland.

Eight: Resources

The National Infertility Support and Information Organisation

P.O. Box 131
Togher
Cork
Ireland

Lo-Call: 1 890 647 444

Lo-call telephone line open from 7pm - 9pm (Mon - Fri)

Phone: 00 353 87 7975058 (*anytime*)

Email: nisig@eircom.net

Web: <http://www.nisig.ie>

Irish Infertility Support Forums (online forum)

Web: <http://www.irishinfertilitysupportforums.ie/>

Clinics

Clane Assisted Conception Unit

Abbeyhall
Fernhust House
Abbey Lands
Clane
Co. Kildare

Phone: 045 989 500

Email: info@claneacu.ie

<http://www.claneacu.ie/index.htm>

Cork Fertilty Centre

Fernhust House
College Road
Cork

Phone: 021 462 4406

Email: info@corkfertilitycentre.com

<http://www.corkfertilitycentre.com/>

Galway Fertility Unit

Brooklawn House
Galway West Business Park
Western Distributor Road
Rahoon,
Galway

Phone: 091 515577

HARI Unit

Rotunda Hospital
Parnell Square
Dublin 1

Phone: 01 807 2732

<http://www.hari.ie>

Kilkenny Fertility Clinic

Greens Hill
Kilkenny

Phone: 056 775 1420

Email: info@thekilkennyclinic.com

<http://www.thekilkennyclinic.com/>

Merrion Fertility Clinic

20 Holles Street
Dublin 2

Phone: 01 678 8688

Email: info@merrionfertility.ie

<http://www.merrionfertility.ie>

Morehampton Clinic

136 Morehampton Clinic
Donnybrook
Dublin 4

Email: morehamptonclinic@eircom.net

<http://www.morehamptonclinic.ie/>

NaPro Technology Medical Centre

The Galway Clinic
Suite 11
Doughiska
Co. Galway

Phone: 091 720 055

Email: info@fertilitycare.ie

<http://www.fertilitycare.ie/>

Scotia Clinic

Scotia House
Manor West
Tralee
Co. Kerry

Email: info@scotiaclinic.com

<http://www.scotiaclinic.com/>

Sims Clinic

Rosemount Hall
Dundrum Road
Dundrum
Dublin 14

Phone: 01 299 3920

Email: info@sims.ie

<http://www.sims.ie/>

Useful Resources

The Report of the Commission on Assisted Human Reproduction

<http://www.dohc.ie/publications/cahr.html>

The Equal Status Act 2000 and 2004

<http://www.equality.ie/index.asp?locID=106&docID=226>

Citizens Information on Fertility Treatment

http://www.citizensinformation.ie/categories/health/women-s-health/fertility_treatment

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Infertility is the single biggest reason for women aged 20-45 going to see their GP, apart from pregnancy itself.

(WHC, 2009)

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