# THE MANAGEMENT OF INFERTILITY IN PRIMARY CARE: CARING FOR PEOPLE WITH A STIGMATISED CONDITION

In this article we present a brief overview of infertility focusing on the anxiety of infertility in the context of current technological interventions. We argue that infertility is a stigmatised condition which makes disclosure difficult for couples. We suggest ways in which primary care nurses may a) assess infertility, b) care for infertile couples who disclose and c) assist with referral to specialist care.

## Introduction

Infertility is a major concern internationally, with an estimated incidence of 9% worldwide (ESHRE 2014). Infertility is a social condition where couples or individuals may not be able to achieve parental or reproductive roles in society; medically it is defined as where pregnancy is not achieved within one year of unprotected sex (The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) 2009).

In this paper we introduce readers to the current debates around infertility and suggest ways in which nurses in primary care could better assess and care for patients who present with infertility issues or those who have had successful pregnancies following assisted reproduction such as in vitro fertilisation (IVF), intra cytoplasmic injection (ICSI), any form of gamete donation such as egg or sperm or surrogacy.

## Infertility: technological interventions and individual anxiety

Fertility treatments such as IVF and ICSI allow many people to achieve parenthood, with over 60,000 cycles of IVF being performed annually in the UK alone (HFEA 2013). Success rates vary considerably due to age and diagnosis, but overall 17,041 cycles result in live births p.a., that is a 25.6% success rate using a woman's fresh eggs (HFEA 2013). All Assisted Reproductive Technologies (ARTs) account for 2% of all live births p.a. IVF/ICSI are complex technologies which, if successful, induce technologically mediated conceptions , yet they are increasingly portrayed as 'routine' (Allan, de Lacey et al. 2009). Allan et al (2009) have argued that while these technologies are common they are not necessarily experienced as routine since they touch on one of the most personal and intimate areas of life – family building (Chodorow 1978, Raphael-Leff 1991, Allan 2001) and involve a fundamental area of reproduction 'normally' kept private (Chodorow 1978, Mohammadi, Shamshiri et al. 2015). In many cases people who are infertile continue to consider themselves infertile, even when they become parents through successful IVF/ICSI. Infertile women experience higher rates of anxiety and depression than fertile women in pregnancy (McMahon C., Tennant et al. 1999, Olshansky 2003, Gameiro, Moura-Ramos et al. 2010) and reduced marital satisfaction

(Sydsjo, Wadsby et al. 2002). Some fathers in IVF/ICSI couples report a negative fathering experience and couples generally report a less positive birth experience (Sydsjo, Wadsby et al. 2002). There is some evidence that repeated attempts at IVF may lower self-confidence in parenting ability (Sydsjo, Wadsby et al. 2002) There is a substantial body of international work investigating the impact of ARTs on couples undergoing treatment (Ulrich, Gagel et al. 2004, Mohammadi, Shamshiri et al. 2015) and growing evidence from international studies of 'non-traditional' families created as a consequence of the use of donor gametes (Golombok, MacCallum et al. 2001).

Becoming a parent for the first time has a life changing impact for men as well as women (Dolan and Coe 2011), often requiring a change in personal experiences and understandings of gender and femininity for women (Mohammadi, Shamshiri et al. 2015); yet the process of transition to fatherhood is under-researched (Culley, Hudson et al. 2013, Marsiglio, Lohan et al. 2013, Dolan 2014, Kowlessar, Fox et al. 2015) and particularly so in the case of ART's. Little is known about how such couples, or men and women within couples whose parenting experiences are intertwined (Miller 2011), experience early parenthood in a social context or how such couples might experience health and describe wellbeing during this first year of parenthood. The literature on ARTs is dominated by a perception of infertility as a medical condition with psychological consequences (Greil, Slauson-Blevins et al. 2010), with infertile people largely studied as infertile 'consumers' of medicine rather than as social beings outside the clinic (Greil, Slauson-Blevins et al. 2010).(Hammarberg, Fisher et al. 2008)(2008) argue that existing studies of early parenting following successful IVF/ICSI do not control for age, social class, ethnicity or the duration of the infertility. Such research which explores such diversity in parenting experience would be helpful for primary care practitioners when planning care to new parents.

***The anxiety of Infertility***

Menning (Menning 1977, Menning 1980) described infertility as a life crisis, a period of disequilibrium. This is typically characterised by a threat to life goals which appears insoluble in the immediate future (Raphael-Leff 1991, Pines 1993) ; it over taxes the resources of the person(s) affected and it may reawaken unsolved psychological problems from the past (Menning 1980). On top of these experiences, the crisis of infertility recurs again and again in cycles of hope, loss and despair. Menning argues that this recurrence can result in adaptive or maladaptive behaviours which elicit coping strategies (Menning 1980). She argues that infertile people experience a syndrome of feelings as they attempt to resolve the infertility crisis. Menning describes these feelings specifically in order: surprise, denial, anger, isolation, guilt, grief, resolution. Menning compares her stages of infertility crisis to Kubler-Ross' stages of dying ((Kübler-Ross 1973). Menning suggests that the loss infertile people experience, while it cannot be felt concretely, is the loss of the imagined child. This

potential loss is not always recognised; it may be socially unspeakable; it can be uncertain; it may not be socially valued as a loss and the infertile person or couple may have no obvious social support system. This imagined loss is as great as the concrete loss of a loved one through death. It is therefore unsurprising that infertile people experience IVF/ICSI and even parenthood, coming as they do after a diagnosis of infertility, as another stressful and anxiety provoking event or series of events.

***Infertility and stigma***

The social condition of infertility (Khetarpal and Singh 2012, Van den Akker 2012) may lead to: stigma and taboo where couples are looked down upon, avoided and find it difficult to disclose to others; the effects of the condition can lead to social isolation and divorce. Primary care nurses need to acknowledge the stigmatised experience of being infertile as infertile people themselves may not be able to disclose their condition (Slade, O'Neill et al. 2007). While there is disagreement over whether infertility is a disease, a disability or a condition which impairs life goals (Khetarpal and Singh 2012), it *is* understood to be a form of disability which entails similar experiences to chronic illness (Greil 1991). The psychological distress that infertile patients may experience is also recognized within the mental health nursing literature ((Hainsworth, Eakes et al. 1994).

There are very few studies exploring the specialist fertility nurses' role and even fewer exploring care of infertile patients in primary care.

**Assessing a couple who are concerned (medical, sexual and social history)**

Slade et al (2007) have suggested that as infertility is a stigmatised condition, infertile couples may feel socially isolated and not feel able to disclose even to health professionals. This is of course important for primary care nurses who may encounter infertile people and couples at every stage during their infertility journey, from the early days of not being to 'fall pregnant' to post successful IVF/ICSI. It is incumbent on the nurse to consider that the patient may be infertile not on the patient to self-disclose (Walker and Allan 2014). Since primary care nurses have an important role in supporting patients in their social and family lives it is essential that they are alert to the possibility of this distressing condition for patients in a wide social milieu. Increasingly, this group will include people for whom parenthood was previously considered unlikely or undesirable; for example survivors of childhood cancers, single sex couples, and those with inherited genetic disorders such as cystic fibrosis.

**When to refer for specialist help**

As we have described, taking the initial step of acknowledging ones' infertility can be traumatic. It may not be disclosed until after many months, or years, of cycles of disappointment and 'trying'. A referral for assessment should therefore be offered to all patients concerned about their fertility, and particularly promptly for older women and those

with a known cause (National Institute for Health and Clinical Excellence (NICE) 2013). For patients with other needs – for example those with childhood cancers wishing to preserve their fertility – their own medical experts will be involved, but their concerns for their future lives and parenthood may be similarly socially constructed. A disclosure of infertility may be equally difficult even in these situations and it may be up to the nurse to introduce this conversation.

For couples experiencing unexpected delays in conception, some reassurance can be offered since the vast majority will achieve pregnancy. This is also a good opportunity for the nurse to provide pre-conception information and offer advice to optimise their chances. Along with lifestyle factors (stopping smoking, folic acid supplementation, healthy BMI) this includes a discussion of frequency and timing of sexual intercourse. These are intimate aspects of people's lives and nurses must remain sensitive to this, including trying to identify, and overcome, the cultural and social barriers which can prevent these exchanges from being useful. Counselling, which is not always easily available in a primary care setting, should be offered if possible.

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