Lived experience of infertility and in vitro fertilisation treatment

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This article is part of a series of articles on infertility.

Background
Infertility is a medical and psychosocial problem that affects one in six couples worldwide. Infertility is increasing largely due to people starting families later, a decrease in the quality of sperm due to environmental and lifestyle factors and rising rates of obesity in both men and women. As a result, general practitioners (GPs) are increasingly seeing patients for fertility-related consultations. Nearly half of these GP consultations will result in a referral to a fertility clinic or relevant specialist. Approximately 5% of children now born in Australia are born as a result of assisted reproductive treatment.

Objective
In Australia, GPs are the primary access point for reproductive care. They can play a central role in educating, preparing and supporting their patients and ensuring timely and appropriate intervention and referral. This paper describes the lived experience of those dealing with infertility, particularly the emotional challenges of infertility and its treatment, to help GPs support their patients throughout treatment and beyond.

Discussion
Infertility and fertility treatment can have a significant impact on the psychological wellbeing of both men and women, as well as their relationships with one another, their family and friends. GPs are well placed to establish a trusting and supportive relationship during one of the most stressful periods of their patients' lives, to notice changes in wellbeing, functioning and relationship satisfaction and to facilitate timely referral to appropriate resources.

INDIVIDUALS AND COUPLES may access assisted reproductive technology (ART) for medical conditions such as multiple miscarriages, endometriosis or polycystic ovaries, to avoid passing on a genetic condition or, in the case of singles or same-sex couples, to access donor or surrogacy treatment. However, women and men are increasingly relying on ART to conceive due to advanced maternal age. A Dutch study published in 2011 found that the proportion of women over 35 years of age attending their fertility clinics had quadrupled between 1985 and 2008.[1]

Although birth rates from in vitro fertilisation (IVF) cycles are continuing to rise due to improvements in technology, ART is simply not able to compensate for the effects of age on fertility. Australian data from 2019 show the significantly higher live birth rate for women under 30 years of age per transfer for autologous fresh cycles than for women aged over 44 years (40% vs 1.7%, respectively).[2] It is important for patients to understand that advanced maternal age reduces ovarian reserve, degrades egg quality and increases chromosomal abnormalities, all of which negatively impact the chances of a healthy live birth.[3]

Despite increased media attention and public education regarding infertility, many wait too long to seek help for fertility issues and then overestimate the capacity of IVF to help them have a baby.[4–7] This can leave them unprepared and ill-equipped for managing the challenges and disappointments often associated with treatment. By the time patients commence IVF treatment, some are already experiencing significant distress and grief due to months, and even years, of trying to conceive and/or multiple miscarriages. This can further impact their ability to withstand what can sometimes be a prolonged and arduous journey to having a child.[8–10]

Psychological impact of ART on men and women

Most patients approach their first IVF cycle with varying (and sometimes unrealistic) levels of optimism and hope that their IVF experience will be a short and successful one, even if their fertility specialist has given them a relatively low chance of success. This

is often due to limited understanding and/or acceptance of the limitations of ART in overcoming some causes of infertility.[4,5,7] Thus, it can come as a shock when a first cycle is completed without a pregnancy. This is often the point where individuals can start to experience greater psychological distress and strain on their relationships (within the couple, but also with extended family and friends). Individuals may also be experiencing other life stressors, such as mental or physical health issues, bereavement or financial stress, which can further impact on their wellbeing.[7,11]

A 2020 study of 1944 men and women undertaking fertility treatment across nine countries, including Australia, found that 60% of respondents reported that fertility treatment had had a significant impact on their mental health and wellbeing.[11] Anxiety was self-reported by 43% of primary patients and 30% of partners. Only 44% of those who reported an impact on their mental health sought help, with Australia having the greatest gap between those reporting mental health issues and those seeking support. Approximately 30% of respondents reported a negative impact of fertility treatment on their relationships, primarily due to emotional strain.[11]

Numerous studies of the lived experience of infertility show there are commonalities in the difficulties men and women experience during treatment, such as feelings of guilt, envy and helplessness. However, women were more likely to struggle with feelings of failure and the challenge of trying to manage their infertility while coping with the rest of their lives.[12] Fertility treatment can have significant impacts on self-esteem, compounded by the lack of control over the outcome of treatment.[8]

Both men and women can struggle with social and cultural expectations around parenthood, but women are particularly affected by societal and personal pressure to fulfil the role of motherhood. Women can feel hurt by perceived insensitive or unhelpful advice; they may feel excluded and left behind by their peers and struggle to participate in social events, especially those involving children. Women can experience grief not only over the loss of the family they imagined, but also the loss of connections with others, control over their body and the ability to plan their life (eg change careers, buy a house or travel). Many women report feeling isolated and alone in their grief.[13]

Although women are more likely than men to experience psychological distress, and at greater levels, it is important that the male experience is acknowledged. Women tend to seek out and receive more social support than men, and a lack of social support can heighten the levels of distress experienced by men.[8]

Men may struggle with not knowing how to support their partners, feeling socially isolated and sometimes forgotten in the treatment regime. They can also carry the burden of being the main support for their partners while simultaneously struggling with their own grief and distress.[11,12]

Men and women often use contrasting coping strategies, which can exacerbate conflict in the relationship. Men tend to cope by distancing themselves from the infertility, keeping their feelings to themselves and focusing on problem solving,[12] so their distress may not be as readily apparent. In our experience, men tend to be more positive and confident of a good outcome, whereas women may prepare for the worst as a self-protective measure.

Can psychological distress affect IVF outcomes?

Women are frequently told that their lack of IVF success is because they are too stressed. However, a recent review of 20 studies found that there was little conclusive evidence that psychological distress before and during treatment negatively affected IVF outcomes.[14] It is important for women (and those around them, including medical professionals) to know this, to help reduce the guilt and self-blame they often feel about their quite normal anxiety and stress.

Regardless of whether psychological distress affects fertility treatment, it can affect quality of life, challenge usual coping strategies and thus decrease the chances of having a baby due to premature withdrawal from treatment.[4,15] Van den Broeck et al[4] found that 'psychological burden' was the main reason respondents gave for discontinuing fertility treatment. Contrary to popular belief, financial burden was far less significant. That study also found that the more anxious and depressed a woman was before beginning IVF treatment, the more likely it was that she would stop treatment after only one cycle.[4]

Similarly, an Australian study found that despite up to six subsidised IVF cycles, the average number of cycles started per patient was only 3.1, regardless of whether a live birth was achieved.[16] The most common reasons given for terminating treatment were 'I had had enough' (66%), 'Emotional cost' (64%) and 'Could not cope with more treatment' (42%).[16] What is clear is that fertility treatments represent a significant upheaval in people's lives: physically, financially, socially, spiritually and emotionally.

What does this mean for GPs?

Regardless of why patients access fertility treatment, their first visit on this path is always to a GP.[17,18] GPs can therefore play a crucial role in early education about fertility, family planning, the effect of age and modifiable lifestyle factors that influence a patient's chances of success.[18-20] GPs can discuss the treatment options available and the limitations of these options and link patients into appropriate and timely interventions. It is also important for GPs to know how to access information about their local IVF clinics, services provided and success rates. Your IVF Success is a government-funded website that is a good source of information for both health professionals and patients seeking unbiased and independent information on all clinics in Australia (www.yourivfsuccess.com.au/).

GPs can be the constant throughout an individual's or couple's IVF journey, from the first discussions about falling pregnant and potential difficulties, throughout treatment and beyond, whether or not they have a child.[19,20,21] GPs are well placed to establish a trusting relationship during one of the most stressful periods of their patients' lives and to notice changes in wellbeing, functioning and relationship

satisfaction. GPs can undertake mental health assessments, develop mental health treatment plans and facilitate timely referral to appropriate resources. The Australian and New Zealand Infertility Counsellors Association has a comprehensive list of fertility counsellors in private practice.

Key points

- There is an increasing reliance on fertility treatments to achieve parenthood.
- Infertility and its treatment present a major upheaval in patients' lives, and patients can experience significant psychological distress as a result.
- GPs can play a significant and constant role throughout an individual's or couple's fertility journey.
- Early identification of fertility issues and timely referral to appropriate resources (eg a fertility specialist and/or fertility counsellor) can help patients achieve successful treatment outcomes and maintain psychological and relationship wellbeing.

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