

# Addressing the emotional barriers to access to reproductive care

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Health care professionals make the medical care of infertility patients a priority, with the goal of achieving a singleton pregnancy for each. Patients who never seek out care, who do not return for treatment after the diagnostic workup, or who drop out of treatment are rarely noticed. Yet this is the outcome for the majority of patients, and the primary reason after financial for treatment termination is the emotional aspect. Attending to the psychological needs of our patients must become a higher priority, to provide all patients true access to care. (Fertil Steril® 2016; ■: ■-■. ©2016 by American Society for Reproductive Medicine.)

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The social and emotional impact of being unable to conceive can be overwhelming. Infertility patients frequently report symptoms of anxiety, depression, isolation, anger, and frustration. The psychological consequences of being unable to conceive can severely impact a person's ability to seek out or remain in infertility treatment. The main times when emotional barriers come into play are [1] delay of or lack of visit to a health care professional when conception does not occur; [2] failure to return for treatment after a first consult with an infertility specialist or after the diagnostic workup; and [3] treatment termination when the prognosis is still optimistic.

The tricky issue is that by definition, health care specialists do not attend to patients who do not come into infertility clinics. Women/couples who never see an infertility specialist are completely off the radar, and those who come in for a consult and/or a

diagnostic workup but do not come back for treatment tend to be unaccounted for. Additionally, patients who drop out of assisted reproductive technology (ART) treatment are also often unaccounted for, or at least not likely to be noticed. As more attention is being paid to this oft overlooked population, important insight has been gained into the reasons for treatment avoidance and passive termination.

## NOT SEEKING CARE AND BARRIERS TO THE FIRST VISIT

For those who struggle with infertility, the path to conception is riddled with stressors and barriers to accessing fertility care. Despite the great advancements being made in the field of assisted reproductive medicine and technology, many couples struggling with infertility remain untreated. Approximately 50% of infertile couples never seek out fertility care, and of

those who do, 20% wait for more than 2 years before seeing a specialist (1). When investigating the reason for these delays it becomes clear that a combination of lack of awareness, denial, and fear play a large role. Fear of failure is one of the greatest emotional barriers preventing patients from seeking fertility treatment (2).

In a survey of 1,010 women who had not yet had a child but had discussed family planning with their physician within the year, the majority overestimated the odds of conceiving per cycle, and 75% of the women were not concerned about being able to conceive. At the same time, 85% of the participants stated that they were willing to pursue infertility treatment if necessary (3). In another survey of 585 couples who had been trying to conceive within the past 24 months, of the couples who had received treatment, 42% waited 6–12 months after physician recommendation to start treatment, 11% waited 18–24 months, and 14% waited more than 24 months (4).

## PSYCHOLOGICAL IMPACT OF TRYING UNSUCCESSFULLY

When 122 consecutive women visiting a fertility center for the first

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time met with a psychiatrist for a structured diagnostic interview, 40% were diagnosed with a psychiatric disorder, the most common being anxiety (23.2%), closely followed by depression (17%). Women who had a psychiatric diagnosis did not differ in age, education, income, or years of infertility (5). In another study of 1,090 consecutive IVF patients who completed a self-report psychiatric questionnaire, 31% had a psychiatric diagnosis, the most common of which was major depression. Only 21% of the women with a psychiatric disorder were receiving any sort of psychological treatment (6).

Although it is understandable that a certain amount of anxiety and depression accompanies infertility, it had been assumed that it was the psychological experience of being unable to conceive that led to the negative emotions. However, it is important to keep in mind that numerous forms of infertility treatment are associated with the development of depressive symptoms. Eighty percent of women taking leuprolide acetate scored in the depressive range on the Hamilton Rating Scale (7), and 75% of women using GnRH agonist medication reported depressive symptoms (8). In a study in Denmark, more than 42,000 women who underwent IVF were assessed for a depression diagnosis; 34.7% had a depression diagnosis before ART, 4.7% were first diagnosed during ART, and 60.7% after ART treatment (9).

In addition to the potential impact of the treatment itself, the social and interpersonal problems often brought about by infertility also contribute to patients' emotional strain. In a European survey of 445 women from France, Germany, Italy, and Spain, of whom 160 were currently receiving treatment, 74% felt resentment when others easily conceived, 67% were tired of receiving suggestions on how to conceive, and 64% felt uncomfortable around pregnant women or babies (2). The majority of patients (55%) reported feeling "inadequate as a woman," and only 24% felt that infertility had made them closer to their partner. This same study asked patients to reflect on their decision to seek treatment and their thought process leading up to that decision; only 32% of the women surveyed had been concerned about the possibility of infertility, 58% felt they waited too long to try to conceive, and the vast majority (81%) of women who saw an infertility specialist wished they had sought out treatment sooner. On average women waited more than 1 year before seeking medical help, with older women seeking out help later than younger women. The most important emotional barrier to treatment was the fear of failure, with 72% of patients citing "being upset if treatments don't work" as a primary concern.

It is also important to note the perceived functional issues influencing patients facing infertility treatment, such as concerns relating to injections, side effects, cost implications, time commitments, and the scheduling of treatments, as well as the possibility of multiple births. Interestingly, aside from scheduling and time issues, women who were not currently in treatment were significantly more likely to cite such functional issues as major concerns than those who were in treatment (2).

## FACTORS ASSOCIATED WITH TREATMENT TERMINATION

In the past it was often assumed that patients only discontinued treatment when they could no longer afford it or when they were advised to do so by their physician (passive termination). The main focus of ART treatment thus far has been on increasing singleton clinical pregnancy rates and not on patient emotional well-being during or after treatment. Now that several states in the United States and numerous countries throughout the world mandate that insurance covers fertility treatment, it has become clear that there are other factors to consider, and the concept of treatment burden has been more widely accepted and investigated.

Recent research indicates that treatment discontinuation rates overall range from 7.7% to 89% (10). Even for insured patients, dropout rates tend to be high, ranging from 46% to 58%. This issue is by no means exclusive to the United States but has been well documented in countries with insurance coverage for IVF. Studies in the Netherlands showed that 32% of patients dropped out before completing three cycles or achieving a pregnancy, in Germany 39% of nonpregnant patients dropped out after the first cycle, and in France more than one-third dropped out after only one cycle (11).

For noninsured patients, cost is usually the number one reason why patients drop out of treatment. However, insured patients cite psychological burden throughout the IVF process as the primary reason for dropping out. There have been many studies that link patient distress and treatment termination. Beginning with studies from 2004, patient distress was the most frequently named reason for treatment termination (12). More recently, in a prospective study of 132 patients under the age of 40 years, who were insured for up to six IVF cycles and who did not initiate a third cycle, the most common reason given for dropping out of treatment was stress (39%), and the top contributors to distress were the toll that infertility took on the couple's relationship and being too anxious or depressed to continue with treatment (13).

A recent review of studies looking into patient dropout found that the top cited reasons were postponement of treatment or unknown (39%), relational and personal reasons (17%), and psychological burden (14%) (14). The main reasons named by patients were related to fear and negative treatment attitudes, including unfavorable attitude about treatment and ethical and moral values. Psychological and emotional factors included pre-existing psychological issues, difficulty coping with negative emotions brought on by unsuccessful treatment, the uncertainty and sense of vulnerability, and the strain of repeated cycles. This strain can also have a negative impact on a couple's relationship. The impact of ART on a relationship and any asymmetry in treatment between partners can add to the emotional turmoil of fertility treatment.

There are many important factors associated with treatment termination. As clinical studies have shown, depressive symptoms before the first cycle can have a significance effect on a patient's ability to withstand multiple treatment cycles (15). Because the emotional and psychological consequences of infertility and the treatment process tend to increase with

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