Addressing the emotional barriers to access to reproductive care

Camilla W. Rich, B.A. and Alice D. Domar, Ph.D.

Domar Center for Mind/Body Health, Boston IVF, Beth Israel Deaconess Medical Center, Harvard Medical School, Waltham, Massachusetts

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;105:1124–7. ©2016 by American Society for Reproductive Medicine.)
Key Words: Access to care, infertility, psychological, stress, treatment termination

Discuss: You can discuss this article with its authors and with other ASRM members at http://fertstertforum.com/richc-emotional-barriers-access-care/

Use your smartphone to scan this QR code and connect to the discussion forum for this article now.*

* Download a free QR code scanner by searching for "QR scanner" in your smartphone's app store or app marketplace.

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

Received January 7, 2016; revised February 9, 2016; accepted February 10, 2016; published online March 30, 2016.
A.D.D. reports grants from Merck; and personal fees from Merck, Johnson & Johnson, Ovascience, and Ferring. C.W.R. has nothing to disclose.
Reprint requests: Alice D. Domar, Ph.D., Harvard Medical School, Beth Israel Deaconess Medical Center, Boston IVF, Domar Center for Mind/Body Health, 130 Second Avenue, Waltham, Massachusetts 02451 (E-mail: domar@domarcenter.com).

Fertility and Sterility® Vol. 105, No. 5, May 2016 0015-0282/$36.00

http://dx.doi.org/10.1016/j.fertnstert.2016.02.017

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

each failed attempt, a biochemical pregnancy or miscarriage from a previous cycle can also influence the decision to terminate treatment even when the prognosis is still optimistic. Additionally, older age and the perception of a poor prognosis play an important role in treatment termination, although the relationship between prognosis and the decision to terminate treatment may not be straightforward. Dropout rates have been shown to increase with the number of frozen embryos; in one study, patients who dropped out of treatment had more frozen embryos than did women who remained in treatment (11).

RECOMMENDATIONS TO DECREASE PATIENT BURDEN

The more we understand about the emotional and psychological hurdles facing patients in need of fertility treatment, the better we are able to help them successfully manage the treatment process.

It is also crucial that patients are referred to an infertility specialist in a timely fashion. Decreasing the time spent in treatment and pinpointing the treatment most likely to achieve a singleton pregnancy can lead to less distress. Practitioners in the reproductive endocrinology and infertility field should increase their efforts to educate referring physicians and nurse practitioners on how to communicate to patients the advantages of receiving specialized care efficiently.

For patients to fully benefit from the successful technologies available, it is essential that they stay engaged and informed throughout the process. There are many ways in which clinics can integrate programs and protocols into their practice to help with this and thus decrease patient burden. Navigating the various elements of infertility and treatment options available can be overwhelming and intimidating, so providing tailored educational and informational materials, including checklists, can help to make sure that all treatment worries are addressed. Specifically, recommendations include: [1] screen high-risk patients for psychological issues; [2] refer those patients for emotional support/counseling; and [3] implement coping interventions for patients (10).

There are many tools and strategies available that providers could implement to improve patient experience and treatment success. SCREENIVF (16) and Fertility Quality of Life (FertiQoL) (17, 18) are two short tools available that can be used to screen and identify at-risk fertility patients. SCREENIVF is an evidence-based, self-administered, 34-item questionnaire addressing five risk indicators for psychological distress during treatment (pretreatment anxiety and depression, negative infertility illness cognitions, low acceptance of infertility, and poor social support) (10). This information is also used to create a risk profile for each patient, identifying their specific vulnerabilities, and a targeted preventive treatment plan (19). FertiQoL is another reliable tool, made up of 26-items, which screens for lifestyle risk factors and helps both clinicians and patients better understand the impact of infertility on patient well-being (emotional, mind, body, relational, and social) (1, 10, 19). FertiQoL is avable online and has been translated into 34 languages (17, 18). Additionally, clinics can identify patients who need to be referred to a mental health professional by using the Hospital Anxiety and Depression Scale, the Beck Depression Inventory, or the Center for Epidemiological Studies-Depression Scale (19). Properly identifying psychological and emotional distress is an essential step in its proper treatment.

Taking into consideration the different learning styles and coping strategies of men and women, a variety of different resources should be available to patients and couples as they navigate this process. Additional tools that can be easily implemented and accessible include preparatory and informational pamphlets, structured checklists, treatment surveys, and educational DVDs that can address popular misunderstandings and fears about treatment and be tailored to target different stages though out treatment (1, 10).

Partner support and involvement throughout the treatment process is a substantial element in relieving patient burden and can be encouraged through couple-based interventions and counseling (20). Given the evidence that relationship strain is a frequent issue for patients in treatment, it is important to ensure the partner is involved. One example of a beneficial therapy for couples is Stress Management and Resilience Training (SMART). A cognitive-behavioral intervention, SMART therapy teaches skills in self-awareness and attention, breathing-based relaxation, and incorporating gratitude, compassion, acceptance, and purpose. In a 2015 randomized clinical trial SMART therapy was proven to be effective in improving generalized and fertility related stress, anxiety, and happiness, significantly improving quality of life measures in both men and women undergoing IVF (21).

Another example of an effective psychological intervention is the Mind/Body Program for Infertility. This is a 10-session cognitive–behavioral/relaxation group intervention designed for infertile women at any stage of treatment; their partners attend three of the sessions. Two randomized, controlled trials have documented the efficacy of this intervention to significantly positively impact pregnancy rates, as well as decrease psychological distress (22–24).

Current research supports the positive effects of a variety of psychological interventions on both patient burden and pregnancy rates. The results of a recently published systematic review and meta-analysis of 39 eligible studies found that psychological interventions, particularly cognitive–behavioral therapy, effectively decrease psychological distress and increase pregnancy rates in infertile women. The authors determined that women who participated in some sort of intervention became pregnant at double the rate as the control women (25).

Additionally, a recent RCT to test the efficacy of a brief psychological intervention (e.g., a stress management packet mailed to participants' homes) showed that intervention participants reported not only significantly lower rates of psychological distress but a decrease in treatment termination rates as well (26).

Continuity of care is key in this ever-expanding field of fertility treatment. It is important for this vulnerable population of patients to feel supported and understood, and ongoing communication between members of their care team is essential. Clinics need to improve staff performance in areas known to impact discontinuation decisions. Finally,

teaching staff stress management skills, using persuasive communication about lifestyle changes, simplifying treatment protocols, and addressing workload issues could go a long way toward decreasing patient burden and increasing success.

In conclusion, the emotional upheaval experienced by those dealing with infertility is immense, and lessening patient burden is an essential step to improving fertility treatment. Not only does the distress brought on by infertility and the subsequent therapy prevent patients from initiating treatment, but it is also the primary reason for many patients to drop out of treatment. Fear of failure creates significant emotional barriers that also prevent patients from seeking fertility treatment; psychological burden is the primary reason for discontinuation. By addressing these obstacles, clinics could see great improvements in patient success, enabling patients to endure the treatments and ultimately improving pregnancy rates.

Acknowledgments: The authors thank Kristin Rooney for her assistance with the preparation of this article.

REFERENCES

1. Boivin J, Gameiro S. Evolution and counseling in infertility. Fertil Steril 2015;104:251–9.
2. Domar AD, Gordan K, Garcia-Velasco J, La Marca A, Barriere P, Beligotti F. Understanding the perceptions of emotional barriers to infertility treatment: a survey in four European countries. Hum Reprod 2012;27:1073–9.
3. EMD Serono. In the know: fertility IQ 2011 survey. Fertility knowledge among US women aged 25-35. Darmstadt, Germany: EMD Serono.
4. Domar AD, Gordon K. The psychological impact of infertility: results of a national survey of men and women. Fertil Steril 2011;95:S17.
5. Chen TH, Chang SP, Tsai CF, Juang KD. Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic. Hum Reprod 2004;19:2313–8.
6. Volgsten H, Skoog S, Ekselius L, Lundkvist O, Sundstrom P. Prevalance of psychiatric disorders in infertile women and men undergoing in vitro fertilization treatment. Hum Reprod 2008;23:2056–63.
7. Warnock JK, Bundren JC, Morris DW. Depressive mood symptoms associated with ovarian suppression. Fertil Steril 2000;74:984–6.
8. Steingold KA, Cedars M, Lu JK, Randle D, Judd HL, Meldrum DR. Treatment of endometriosis with a long-acting gonadotropin-releasing hormone agonist. Obstet Gynecol 1987;69:403–11.
9. Sejbaek CS, Hageman I, Pinborg A, Hougaard CO, Schmidt L. Incidence of depression and influence of depression on the number of treatment cycles and births in a national cohort of 42 880 women treated with ART. Hum Reprod 2013;28:1100–9.
10. Boivin J, Domar AD, Shapiro DB, Wischmann TH, Fauser BCJM, Verhaak C. Tackling the burden of ART: an integrated approach for medical staff. Hum Reprod 2012;27:941–50.
11. Troude P, Guibert J, Bouyer J, de la Rochebrochard E, DAIFI Group. Medical factors associated with early IVF discontinuation. Reprod Biomed Online 2014;28:321–9.
12. Domar AD. Impact of psychological factors on dropout rates in insured infertility patients. Fertil Steril 2004;81:271–3.
13. Domar AD, Smith K, Conboy L, Iannone M, Alper M. A prospective investigation into the reasons why insured United States patients drop out of in vitro fertilization treatment. Fertil Steril 2010;94:1457–9.
14. Gameiro S, Boivin J, Verhaak CM. Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. Hum Reprod Update 2012;18:652–69.
15. Smeenk JM, Verhaak CM, Stolwijk AM, Kremer JA, Braat DD. Reasons for dropout in an in vitro fertilization/intracytoplasmic sperm injection program. Fertil Steril 2004;81:262–8.
16. Verhaak CM, Lintsen AM, Evers AW, Braat DD. Who is at risk of emotional problems and how to know? Screening of women going for IVF treatment. Hum Reprod 2010;25:1234–40.
17. Biovin J, Takefman J, Braverman A. The fertility quality of life (FertiQoL) tool: development and general psychometric properties. Hum Reprod 2011;26:2084–91.
18. Biovin J, Takefman J, Braverman A. FertiQoL international: fertility quality of life questionnaire. Available at: http://sites.cardiff.ac.uk/fertiqol/download. Accessed February 2, 2016.
19. Gameiro S, Biovin J, Domar A. Optimal in virto fertilization in 2020 should reduce treatment burden and enhance care delivery for patients and staff. Fertil Steril 2013;100:302–9.
20. Markins MV, Peterson BD, Almeida V, Mesquita-Guimaraes J, Costa ME. Dyadic dynamics of perceived social support in couples facing infertility. Hum Reprod 2014;29:83–9.
21. Khan Z, Fuehrer D, Coddington C, Bleess J, Daftary G, Stewart E, et al. Stress Management and Resilience Training (SMART) therapy for couples undergoing in vitro fertilization (IVF): a randomized clinical trial (RCT). Fertil Steril 2015;104:e42.
22. Domar AD, Clapp D, Slawsby E, Kessel B, Orav J, Freizinger M. The impact of group psychological interventions on distress in infertile women. Health Psychol 2000;19:568–75.
23. Domar AD, Clapp D, Slawsby EA, Dusek J, Kessel B, Freizinger M. Impact of group psychological interventions on pregnancy rates in infertile women. Fertil Steril 2000;73:805–11.
24. Domar AD, Rooney KL, Wiegand B, Orav EJ, Alper MM, Berger BM, et al. Impact of a group mind/body intervention on pregnancy rates in IVF patients. Fertil Steril 2011;95:2269–73.
25. Frederiksen Y, Farver-Vestergaard I, Skovard NG, Ingerslev HJ, Zachariae R. Efficacy of psychosocial interventions for psychological and pregnancy outcomes in infertile women and men: a systematic review and meta-analysis. BMJ Open 2015;5:e006592.
26. Domar AD, Gross J, Rooney K, Biovin J. An exploratory randomized trial on the effect of a brief psychological intervention on emotions, quality of life, discontinuation and pregnancy rates in IVF patients. Fertil Steril 2015;104:44051.