

A prospective investigation into the reasons why insured United States patients drop out of in vitro fertilization treatment

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Objective: To determine the primary reason why insured patients drop out of IVF treatment in the United States and to identify methods to decrease such behavior.

Design: Prospective patient survey.

Setting: Private infertility clinic.

Patient(s): Women under the age of 40 years, who had insurance coverage for at least three IVF cycles, who did not conceive and who did not return to the clinic for a third treatment cycle.

Intervention(s): One hundred thirty-two eligible patients received a study packet of questionnaires in the mail.

Main Outcome Measure(s): Subject responses to questionnaire.

Result(s): Forty-seven subjects returned the questionnaire. The most common reason for terminating treatment was stress (39%). Subjects reported that the two main causes of stress were the toll that infertility took on the couples' relationship and being too anxious or depressed to continue. The top-rated suggestions for patient support were written information on how to deal with psychological stress and easy and immediate access to a psychologist or social worker.

Conclusion(s): Patients undergoing IVF in the United States report similar reasons for terminating treatment as patients in Europe and Australia. However, this is the first study to gather patient suggestions for treating the problem. (Fertil Steril® 2010;94:1457–9. ©2010 by American Society for Reproductive Medicine.)

Key Words: IVF, drop-out, treatment termination, patient distress, stress

Infertile individuals and couples are considered to be highly motivated in their pursuit of a successful pregnancy. Patients repeatedly put themselves through rigorous treatment protocols, and many health care professionals have the impression that IVF treatment is terminated for only three reasons: pregnancy, cost, or the refusal of the physician to continue treatment because of a poor treatment response or prognosis (active censoring). Many reproductive endocrinologists are unaware of the number of patients that fail to return for treatment because it is very difficult to track patients who are lost to follow-up. However, research has shown that, in fact, a significant number of patients terminate treatment of their own volition and not for financial reasons (1). Active censoring by physicians is a relatively uncommon reason for termination. A 1997 study from the Netherlands, where assisted reproductive technology costs are covered by insurance, determined that the cumulative dropout rate after

three cycles was 62%, only 13.9% of which was due to active censoring (2). A subsequent study, also in the Netherlands, determined that there was no evidence for selective dropouts due to poor treatment prognosis (3).

Although the prevalence of patients who choose to terminate treatment is surprisingly high, psychological burden is the main reason cited consistently across studies and countries. A study of 974 couples in Sweden who each had three covered IVF cycles revealed that 65% of the couples did not achieve a live birth but did not avail themselves of the full treatment program (4). The reason for declining further free treatment was not established, but the authors proposed that the burden of treatment was too much for the couples to bear. An Australian study produced similar results (5). Although patients were offered six IVF cycles free of charge, the average number of started cycles was only 3.1, regardless of whether a live birth was achieved. The most common reasons for terminating treatment were "I had had enough" (66%), "emotional cost" (64%), and "could not cope with more treatment" (42%). In another Swedish study, 54% of patients discontinued IVF treatment before completing three covered cycles or achieving a pregnancy (6). The most commonly cited reason for termination was psychological burden, followed by perception of poor prognosis.

Because the majority of patients who drop out of treatment do so because of the psychological burden, it is important not only to determine what the source of stress is but also to attempt to determine whether there are any actions that could have been taken to lessen the perceived psychological burden and thus allow patients

Received March 25, 2009; accepted June 8, 2009; published online July 9, 2009.

A.D.D. has performed consulting for Schering Plough and received grant support from Johnson and Johnson. M.A. has performed consulting for EMD Serono. K.S. has nothing to disclose. L.C. has nothing to disclose. M.I. has nothing to disclose.

Supported by Organon Pharmaceuticals, the Netherlands.

Presented at the 62nd Annual Meeting of the American Society for Reproductive Medicine, New Orleans, Louisiana, October 21–25, 2006.

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to remain in treatment. Potential sources of stress might include the impact on the couple's relationship, transportation issues, psychological consequences of the infertility itself, an inability to withstand more invasive procedures, or fear about the potential side effects of medications or treatment. Once the source of stress is identified, interventions designed to decrease the distress can be implemented.

The purpose of this prospective study was to determine the causes for discontinuation of IVF treatment before exhausting insurance-covered cycles in a US population of patients, as well as to determine what potentially could have been done to encourage or support patients to continue treatment. If the reasons for IVF treatment termination can be discovered and remedied, the numbers of patients who continue with IVF treatment should increase, leading to increased numbers of pregnancies and patient satisfaction.

MATERIALS AND METHODS

This study was approved by the Committee on Clinical Investigations of Beth Israel Deaconess Medical Center through full-board review. All treatment was provided at Boston IVF, a large private academically affiliated IVF center.

All Boston IVF patients who began their first IVF cycle between June 1, 2004, through November 2005 were included in the study. Patients over the age of 40 years and those using testicular biopsy were excluded. A year after each eligible subject started her first cycle, her record was assessed to see whether she fulfilled the study criteria: at least three IVF cycles covered by her insurance; did not conceive a viable pregnancy; and did not commence a third IVF cycle (subjects who did one or two IVF cycles during the observation year).

A total of 390 cycle starts were observed, of which 128 women fulfilled the eligibility criteria noted above. Each of these 128 women was mailed a study packet, which included a cover letter of explanation with implied informed consent, as well as the study questionnaire. The packet included two stamped envelopes; subjects were instructed to address one if they would like to receive a complimentary relaxation CD as a small token of appreciation for participation, and to mail it inside the other self-addressed one.

The study questionnaire had five sections. Section 1 included general demographic questions. Section 2 asked for one reason for treatment termination; choices included switching to a different IVF center; a decision to move on to adoption, gamete donation, or child-free living; physician recommendation; psychological burden; loss of insurance coverage; a need to take a break from treatment; or other. The remaining three sections included questions that pertained only to subjects who reported terminating treatment because of psychological burden. Subjects were asked to note the primary and secondary causes of the psychological burden; choices included taking too much of a toll on the relationship, transportation challenges, feeling too anxious or depressed to continue, feeling that she had already given IVF her best chance, inability to

tolerate the side effects of medication, the injections, nervousness about potential long-term treatment consequences, or other. In addition they were asked about the stress induced by the medication regimen. They also were asked to note what they thought might have helped them be able to continue with treatment and were given a variety of answers to choose from, including more access to their physician, stress reduction classes, written stress management materials, more nursing access, easy access to a mental health professional, and more convenient clinic locations.

RESULTS

A total of 47 subjects returned the study questionnaire, a 37% response rate. The overall dropout rate of Boston IVF patients was 34%; that is, 34% of patients who had insurance coverage for at least three cycles completed only one or two cycles despite having not achieved a pregnancy. Six of the subjects reported that they had "dropped out" of treatment because of pregnancy achieved spontaneously or at another clinic and therefore were excluded from the analysis; thus the results were based on the group of 41 women.

The mean age of the remaining 41 subjects was 36 years, with a range of 20 to 41 years. The mean duration of infertility was 3.8 years, and the mean duration of treatment was 2.1 years. The mean number of years of education was 15.9. The most common diagnosis was unexplained infertility (39%) with 24% reporting a diagnosis of male factor, 17% reporting high FSH, 12% reporting endometriosis or a tubal factor, and the remaining reporting "other" (e.g., ovulatory disorder, polycystic ovary syndrome).

The most common reason given for terminating treatment was emotional: psychological burden (22%) and needing to take a break from treatment (17%), or a total of 39% of the sample. A total of 27% of the subjects changed IVF centers, 10% lost insurance coverage, 5% decided to pursue adoption or third-party conception, 5% were advised by their physician to stop, several patients moved out of state, and 10% gave no reason.

Participants who noted that the primary reason they dropped out of treatment was the psychological burden were asked to specify the most stressful part of the process (Table 1). The two most common answers were "infertility taking too much of a toll on our relationship" and "too anxious or depressed to continue." The least likely reason was "I could not stand all of the injections." When asked for a specific reason why the medications led to stress, the most commonly given answer was "injecting medication," followed by "needing to have injection when away from home." The least commonly picked reasons were "presence of bubbles in the medication after mixing" and "possibility of spilling medication."

TABLE 1

Reported primary and secondary sources of treatment stress: Subjects listed their primary and secondary sources of stress with treatment if they had one.

Cause of stress	No. of subjects who listed as primary cause	No. of subjects who listed as secondary cause
Infertility taking too much of a toll on our relationship	3	1
It was too difficult to get to IVF center so often.	1	1
Too anxious or depressed to continue	3	0
I had already given IVF my best chance.	1	1
I could not stand side effects of medication.	1	2
I could not stand all of the injections.		1
I was getting nervous about possible long-term effects of treatment.	0	2
Other (subjects listed: cost of medications and donor sperm)		1

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TABLE 2**Subject-endorsed ways to improve their experience.**

Need endorsed	Count
More access to my doctor	2
Written information on how to deal with stress/psychological issues	5
More convenient treatment location	3
Evening or weekend office hours	3
Stress reduction class or classes	3
More access to my IVF nurse coordinator	1
Drop-in evening groups for peer support	2
Easy immediate access to a psychologist or social worker	5
Any other ideas? (subjects listed: medications not right for me; would have liked a female doctor; lack of belief in treatment)	2

Note: Count of subjects who endorsed a need that if met would have made their experience better. Subjects could choose as many categories as necessary.

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Subjects also were asked to note how Boston IVF could have made their experience better (Table 2). The two most frequent answers were “written information on how to deal with stress/psychological issues” and “easy immediate access to a psychologist or social worker,” followed by “stress reduction class or classes” and “more access to my IVF nurse coordinator.” Two of the choices chosen least frequently were “more locations” and “a female doctor.”

As part of the quality control component of the study, each subject’s medical chart was reviewed to make sure that she was a true dropout and had not stopped treatment for another reason. The number of subjects who did not return for treatment but who still had frozen embryos on site was noted. Twenty percent of the study subjects had frozen embryos remaining; 3 years later that number had dropped to 5%. Thus, six subjects who took a minimum of a year off from treatment did in fact return at a later date for a frozen ET. Of the 128 subjects who had been mailed a study questionnaire, 30% had frozen embryos at the end of the year, and half of them returned within the following 3 years for a thaw cycle.

DISCUSSION

One of the problems in addressing the issue of dropouts from infertility treatment is the terminology. Women and couples who make the decision to stop treatment have been referred to as treatment discontinuers, rejecters, therapy terminators, premature terminators, and simply as dropouts. Because the word *dropout* can have a negative connotation, it has been proposed by some researchers that these patients be referred to as discontinuers, since in fact the decision to terminate treatment can be the culmination of a careful and positive deliberative process.

Research in the field has focused mainly on cumulative pregnancy rates, yet the psychological status of the patient having IVF appears to have the greatest impact on how many cycles she undergoes (7). If the patient’s pretreatment psychological state is closely associated not only with treatment success but also with her ability to remain in treatment, why is it that the psychological needs and emotional stability level go unmeasured and unaddressed?

The current study goes a step further than the previous research not only in concurring that the main reason that insured patients having IVF discontinue treatment is the psychological burden, but in indicating that providing psychological support through written materials and the presence of trained mental health professionals might have led patients to make a different decision, that is, that they might have been able to remain in treatment. The obvious next step is to follow through on these suggestions. Future research should investigate the impact of either or both of these suggestions on discontinuation rates in patients having IVF.

It is noteworthy that when data were being collected for this study, it was observed that the discontinuation rate for patients aged 40 to 42 years having IVF was 68%, exactly twice what it was for the study sample of women under the age of 40 years. During the study period, the per cycle pregnancy rate per cycle start for women in this age group at Boston IVF was 25%; therefore, active censoring by the physician was likely not a major factor. Thus, research on dropout behavior and prevention needs to include and address the concerns of women in this age group as well.

There were some study limitations. The sample size was smaller than anticipated. Fewer patients met the study criteria during the recruitment year than had been forecast, and it had been hoped that the offer of a free relaxation CD would entice more than a third of the eligible subjects to complete the questionnaire. Thus, the results of this study are based on a small sample size. The response rate was 34%, which is not unusual for this type of questionnaire study. However, it is also not known whether the actual study respondents were representative of the sample. It is possible that women who returned the questionnaire were somehow different from the women who did not and that women who discontinued treatment because of the psychological burden were more likely, or perhaps even less likely, to return the questionnaire, thus biasing the results. However, because the results presented here indeed replicate the results from all of the other studies in this area, this is a somewhat unlikely scenario.

In conclusion, the results of this study confirm previous findings that patient distress is the primary reason patients with complete insurance coverage having IVF make the decision to discontinue treatment. It is possible that providing patients with psychological support, in either written or personal form, might allow them to remain in treatment, but intervention research is necessary.

Acknowledgments: The authors thank the following for their support in the design, implementation, and analysis of this study: R. Doug Powers, Ph.D., Ms. Kristin Backman, Alan Penzias, M.D., Ms. Lauren Prince, and Shunping Wang, Ph.D.

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