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Burden of care is the primary reason why insured women terminate in vitro fertilization treatment

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Abstract

Objective: To study the reason(s) why insured patients discontinue in vitro fertilization (IVF) before achieving a live birth.

Design: Cross-sectional study.

Setting: Private academically affiliated infertility center.

Patient(s): A total of 893 insured women who had completed one IVF cycle but did not return for treatment for at least 1 year and who had not achieved a live birth were identified; 312 eligible women completed the survey.

Intervention(s): None.

Main Outcome Measure(s): Reasons for treatment termination.

Result(s): Two-thirds of the participants (65.2%) did not seek care elsewhere and discontinued treatment. When asked why they discontinued treatment, these women indicated that further treatment was too stressful (40.2%), they could not afford out-of-pocket costs (25.1%), they had lost insurance coverage (24.6%), or they had conceived spontaneously (24.1%). Among those citing stress as a reason for discontinuing treatment (n = 80), the top sources of stress included already having given IVF their best chance (65.0%), feeling too stressed to continue (47.5%), and infertility taking too much of a toll on their relationship (36.3%). When participants were asked what could have made their experience better, the most common suggestions were evening/ weekend office hours (47.4%) and easy access to a mental health professional (39.4%). Of the 34.8% of women who sought care elsewhere, the most common reason given was wanting a second opinion (55.7%).

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Conclusion(s): Psychologic burden was the most common reason why insured patients reported discontinuing IVF treatment. Stress reduction strategies are desired by patients and could affect the decision to terminate treatment. (*Fertil Steril*® 2018;109:1121–6. ©2018 by American Society for Reproductive Medicine.)

Keywords

IVF; treatment termination; infertility; psychologic burden

Despite more than two decades of published literature on treatment discontinuation among patients undergoing infertility treatment, there are limited data on why patients discontinue treatment (1). Many health professionals in the infertility field think that patients discontinue treatment because of an inability to pay and/or a poor prognosis. Although most research on uninsured patients supports the hypothesis that finances play a large role in the decision to discontinue treatment, a series of studies published in 2004 found that perceived poor prognosis or physician recommendation were not primarily responsible for treatment termination (2–5). In fact, in each of those studies of insured patients, patients reported that the negative psychologic aspect of treatment was the primary reason for terminating treatment. The majority of subsequent studies have replicated these findings, with insured patients consistently reporting that stress (sometimes referred to as emotional burden or the burden of care) is the primary reason why they decide to leave treatment (6, 7). To improve patient care, it is important to go beyond determining that “stress” is the primary reason for treatment termination. It is also important to identify precisely the main stressor(s) that contributed to the decision and, perhaps most importantly, what patients think might have allowed them to continue treatment.

A previous small prospective study conducted at our center (7) identified stress as the most common reason for terminating treatment, with the two main stressors being the toll that infertility took on the relationship and/or being too anxious or depressed to continue. The most commonly cited suggestions for patient support were written information on how to deal with stress and easy and immediate access to a mental health professional. However, a replication study with a larger cohort of patients is needed before making definitive conclusions or recommendations.

The aim of the present study was to determine the primary reason(s) why a large cohort of insured patients discontinued IVF treatment before achieving a live birth. Furthermore, because previous research has indicated that treatment termination is associated with older age (8), a secondary aim of this study was to examine the reasons for treatment discontinuation stratified by patient age.

MATERIALS AND METHODS

We included all women who were 18–42 years of age at the time of their final in vitro fertilization (IVF) cycles at Boston IVF—a large academically affiliated infertility clinic—from January 1, 2010, through May 31, 2014, who did not return for treatment for at least 1 year and who did not achieve a live birth from any IVF cycle at our center. Those who ever used donor oocytes or a gestational carrier were excluded. Women were stratified into the

following age groups based on their age at the start of their last cycle: <30 years, 30 to <35 years, 35 to <40 years, and 40–42 years.

All women whose e-mail address was included in their contact information were e-mailed an invitation to complete an online survey that was modified from our previous study(7) and included questions regarding whether the woman sought care after leaving our center and the reasons why or why not. Additional questions assessed specific sources of stress inherent in the treatment process, as well as suggestions to improve care for future patients. The questions about the decision to drop out of infertility treatment, sources of stress, and potential antidotes to stress were identical to the questions asked in the original study. The reason for this is that this study was designed as a replication study with a far larger patient sample and with the addition of stratification by age.

Altering the questions in the survey to reflect more current research on patient treatment termination was considered. There have been a number of studies in Europe which have attempted to identify the system factors most cited by patients as factors considered to be most important concerning treatment adherence and palatability. The factors included in the various research studies were information provision, staff competence, coordination and continuity of care, accessibility, physical comfort, staff attitude, patient involvement, privacy, and emotional support (9, 10). Patient-centered care guidelines were proposed based on input from patients and health professionals (11). Patients chose 16 priorities and health professionals chose 18. There were only five that overlapped: need to perform intrauterine insemination R6 days per week, reporting on treatment outcomes, standardized semen analysis reporting, counseling on harmful lifestyle habits, and information on the risks of a high body mass index. In a follow-up intervention study, one-half of 32 Dutch clinics integrated a “multifaceted improvement strategy for patient-centered care” for 1 year (12). However, patients did not report an improvement in patient-centered care. Therefore, our research team made the decision to not change the research questions used in the original study, because the results from that pilot study were consistent with other studies.

Nonrespondents were sent an e-mail reminder 1 week after the initial e-mail. Women who did not respond to either e-mail were sent a physical letter inviting them to complete the survey online. Nonrespondents were called starting 1 week after the letters were mailed, and a second call was made as necessary R1 week after the first call. In addition, owing to the small sample size of women under the age of 30 years, all eligible women under age 30 whose contact information did not include an e-mail address were contacted by mail asking them to complete the survey online, and nonresponders were contacted by telephone.

Survey responses were collected in REDCap, a web-based data capture tool hosted at Beth Israel Deaconess Medical Center (13). Descriptive data are presented as median (interquartile range [IQR]) or as n (%). The analysis was restricted to women with full or partial insurance coverage for IVF. P values <.05 were considered to be statistically significant, and all tests were two sided. All analyses were conducted with the use of SAS 9.4 (SAS Institute). The Institutional Review Board at Beth Israel Deaconess Medical Center approved this study.

RESULTS

A total of 893 eligible women were identified; 383 women completed the survey, yielding a response rate of 42.9%. Respondents did not differ from nonrespondents regarding age at first cycle ($P=.98$) or primary infertility diagnosis ($P=.37$). Of these 383 women, 312 (81.5%) had full or partial insurance coverage for their IVF treatment and were included in the final analysis. There were 28 (9.0%) women <30 years, 85 (27.2%) women 30 to <35 years, 121 (38.8%) women 35 to <40 years, and 78 (25.0%) women 40–42 years of age at the time of their last IVF cycle. Parity tended to increase with age. The youngest women reported a slightly shorter median duration of infertility before starting treatment compared with the other three age groups (Table 1).

After discontinuing treatment at our center, approximately one-third (34.8%) of insured women reported seeking further care, while approximately two-thirds (65.2%) did not seek further care. Although the proportion of women seeking further care declined with age (42.9%, 39.3%, 37.9%, and 22.1% among women aged <30, 30 to <35, 35 to <40, and 40–42 years, respectively), the proportions did not differ significantly ($P=.06$). Among the women who reported seeking care elsewhere, the most common reason reported was the desire for a second opinion (55.7%), followed by not being happy with their care (40.6%) and having heard good things about another center (27.4%). Although none of the reasons for seeking care elsewhere differed significantly by age (all $P .12$), the youngest women were the most likely to want a second opinion and to have heard good things about another center and the least likely to be unhappy with their care (Table 2).

Among the women who reported not seeking further care, the most common reason was that further treatment was too stressful (40.2%). This differed significantly by age ($P=.03$), with the youngest and oldest women being less likely to report this reason (12.5% and 33.3%, respectively) than women aged 30 to <35 years (45.1%) or 35 to <40 years (48.6%). The next most common reason, not being able to afford the out-of-pocket costs (25.1%), also differed significantly by age ($P=.01$), as did being advised to stop treatment ($P=.01$), which was highest among women aged 40–42 (25.0%) compared with younger women (3.9%–13.9%). Out-of-pocket costs for insured patients include co-pays and deductibles and can range per cycle from as little as \$20 to thousands of dollars if a patient has a large copay or deductible. Overall, 24.1% of women reported not seeking further care because they conceived spontaneously; this did not differ by age ($P=.23$). Interestingly, 18.3% of women aged 40–42 reported spontaneous conception as a reason for not returning to care. None of the remaining reasons for not seeking further care differed by age (all $P .06$; Table 3).

When asked for the single most important reason why they did not seek further treatment, the most common response was spontaneous conception, and this was most commonly reported by women <30 years of age (38.5%). None of the single most important reasons differed significantly by age (all $P .07$; Table 3).

For the 40.2% of women who reported that further treatment was too stressful, when asked about specific sources of this stress, nearly two-thirds (65.0%) reported that they “had already given IVF my best chance.” Nearly one-half (47.5%) reported being too anxious or

depressed to continue treatment, and more than one-third (36.3%) reported that infertility was taking too much of a toll on their relationship. Age was significantly associated with reporting that treatment was too expensive ($P=.04$), with 40% of women aged 40–42 reporting this source of stress compared with 0%–17.4% of younger women. None of the other specific sources of stress differed by age (all $P .07$; Table 4). Although many respondents reported having “other” sources of stress, the descriptions of this stress was often more detailed explanation of a specified source of stress that was also selected (e.g., one respondent selected “I was too depressed or anxious to continue” and “other” and specified in the “other” description that “recurrent miscarriages were depressing and too stressful/upsetting, so we decided to pursue adoption and have since adopted two children”).

Finally, all women were asked what could have made their treatment better. Nearly one-half (47.4%) wanted evening or weekend hours, and 39.4% wanted easy and immediate access to a psychologist or social worker. With the exception of having more access to the IVF nurse coordinator, which differed significantly by age ($P=.03$) and was more common among the two younger age groups (32.9%–39.3%) than the two older age groups (18.2%–24.4%), none of the suggestions differed by age (all $P .18$; Supplemental Table 1, available online at www.fertstert.org). As with sources of stress, many patients indicated that “other” things would make their treatment better and these often overlapped substantially with choices that had been selected (e.g., one respondent selected “more access to my doctor” and “other” and specified in the “other description” that it was “very difficult to get in touch with my doctor, and when we had a negative result it took him a long time to contact us”).

DISCUSSION

Psychologic stress was the most common reason reported by insured women for stopping infertility treatment. Even though stress was the primary reason for terminating treatment, the financial component remains very important. When examining the reasons why women did not seek further care, out-of-pocket costs and loss of insurance were the next most common reasons after stress. Surprisingly, the incidence of natural conception was high and was the single most important reason why respondents stopped treatment. Psychologic stress, financial constraints, and losing insurance coverage all differed by age.

Although patients decide to terminate treatment for a variety of reasons, these results are consistent with previous research demonstrating that stress is the most common reason insured women terminate treatment (7). A recent systematic review found the most common reasons to be postponement of treatment, physical and psychologic burden, and relational issues (1).

Treatment termination, defined as the decision to discontinue treatment despite a favorable prognosis and the ability to pay for treatment (14), has been a challenging issue for many years. Patients who terminate treatment before achieving pregnancy may regret losing their chance to have their own biologic child. Our results show that in a setting of excellent health insurance coverage, stress still plays a dramatic role in couples deciding to terminate treatment. Previous research has shown that almost one-half of patients who terminated treatment were not satisfied with their decision(15), and most felt that they lacked adequate

support to make the decision (16). In addition to ramifications for patients, treatment termination has a direct financial impact on the clinic.

The perception of treatment termination can vary widely. In one meta-analysis of adherence with assisted reproductive technologies (17), the authors modeled the difference in cumulative incidence of pregnancy after three cycles between couples who stayed in treatment versus those who did not. They reported that for every 100 couples starting assisted reproductive technology (ART) treatment, 78 remained in treatment for the prescribed three cycles. Of these 78, 43 experienced a clinical pregnancy or live birth. However, if all couples had remained in treatment, the authors hypothesized that 58 would have achieved success, yielding a 15% increase in the incidence of pregnancy or live birth.

Interestingly, we found that 21–33% of patients under age 40 conceived spontaneously, as did 18% of those aged 40–42 years.

Predicting which patients are most likely to terminate treatment is the subject of much speculation, because one could presumably intervene to alter the behavior of the patients most at risk of stopping treatment. Two recent studies addressed the issue of risk identification. The first examined medical factors and identified older age, an infertility history of >5 years, female-factor or unexplained infertility, zero or one oocyte retrieved, and no embryo transfer as risk factors(18). In the second study, which assessed medical and psychologic factors, female age and depression were the strongest predictors of termination, whereas female education level, greater engagement in ART, and female-factor infertility were associated with a decreased risk of treatment termination (8). Many studies of treatment have identified older age as a risk factor, which makes sense because prognosis decreases with age and prognosis is associated with termination. However, if treatment termination were due solely to poor prognosis, then young women would be the least likely to stop treatment, which is not the case. We previously found that although women aged 40–42 years were the most likely to stop treatment, women <30 years old were as likely to stop treatment as those aged 30 to <40 years, indicating that factors other than prognosis affect decision making (19). However, women aged <30 and 40–42 years were the least likely to report stress as the reason why they terminated treatment.

The limitations of the present study include a response rate of fewer than one-half of eligible patients, and the reasons for treatment termination reported by participants may differ from those of nonparticipants. However, respondents and nonrespondents did not differ regarding to age or primary infertility diagnosis. Another limitation is that all patients were treated at one large infertility center, and it is possible that women who receive care at other centers may have different reasons for stopping treatment. The study also was underpowered to detect differences by age for some secondary analyses, because there were fewer women <30 and >40 years of age. Although the use of the same questions used in a prior pilot study made the results comparable, the questions did not incorporate some of the patient-centered care suggestions noted in recent research. However, the lack of consensus regarding which aspects of care improvement positively affect the patient experience would have made including these aspects challenging. Finally, insurance coverage for up to six IVF cycles is unusual in the U.S., and the results from this study may be generalizable only to patients

who have generous insurance coverage. The strengths of this study are the relatively large sample size and the ability to compare results by age.

The obvious next step is to explore effective ways to decrease stress in women undergoing IVF. Ironically, the women who participated in this study received IVF treatment at Boston IVF, which has a large integrative care center located at its main office. On-site psychologists are available during the week for regular appointments and crisis counseling, which is available within an hour of the request, and every patient who has an unsuccessful cycle can see a psychologist for a free 30-minute visit. In addition, acupuncturists are available daily. There are evening stress reduction classes and written information on decreasing stress. However, most patients do not avail themselves of these services, indicating a clear disconnection between services that patients report wanting and those that they utilize. It is obvious that the services offered are not exactly meeting the needs of the most vulnerable patients.

Although there are dozens of studies that focus on interventions to decrease stress and/or increase pregnancy rates, there is a paucity of research on interventions addressing treatment termination. In a recent study of 166 women about to begin their first IVF cycle (20), women were randomized to routine care or an intervention group receiving cognitive coping and relaxation strategies. Participants were followed for 12 months, and although the pregnancy rates were equivalent, 15.2% of the routine-care patients discontinued treatment compared with only 5.5% of the group receiving cognitive coping and relaxation strategies. In addition, the intervention group had significantly better coping, increased quality of life, and less anxiety.

CONCLUSION

The results of this study replicate previous research documenting the impact of stress on the decisions of insured infertility patients to terminate treatment. The present study describes the specific contributors to the perceived stress and includes valuable suggestions from patients as to what may be offered to decrease their likelihood of stopping treatment. The next step is to investigate which psychologic interventions are the most effective and cost-efficient in supporting patients to continue treatment until they achieve a viable pregnancy or it is medically advisable to stop treatment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Participant characteristics at the start of the first in vitro fertilization cycle, stratified by age at the start of the last in vitro fertilization cycle.

Characteristic	<30y (n = 28)	30 to < 35 y (n = 85)	35 to <40y (n = 121)	40 to < 43 y (n = 78)
Age, y	27.9(26.6–29.1)	32.5 (30.8–33.7)	36.9 (35.6–38.5)	40.8 (40.0–41.6)
Partner age, y	30.0 (28.0–32.0)	33.0(31.0–36.0)	37.0 (34.0–39.0)	40.0 (36.0–43.0)
Body mass index, kg/m ²	24.1 (21.6–29.6)	27.1 (23.2–30.2)	25.7(22.0–31.2)	25.4 (23.0–34.0)
Gravidity				
0	15(53.6)	47 (55.3)	60 (50.0)	33 (42.3)
1	8(28.6)	18(21.2)	31 (25.8)	17(21.8)
2	5(17.9)	20(23.5)	29 (24.2)	28 (35.9)
Parity				
0	24 (85.7)	67 (79.8)	90 (75.0)	55 (70.5)
1	2(7.1)	15(17.9)	28(23.3)	19(24.4)
2	2(7.1)	2 (2.4)	2(1.7)	4(5.1)
Months of infertility	12.0(9.0–24.0)	17.0(12.0–36.0)	18.0(12.0–26.0)	18.0(12.0–24.0)
Insurance coverage				
For all treatment	17(60.7)	56 (65.9)	94(77.7)	42 (53.8)
For some treatment	11(39.3)	29(34.1)	27(22.3)	36 (46.2)
Highest level of education				
Less than high school	0 (0.0)	2 (2.4)	0 (0.0)	0 (0.0)
High school graduate	2(7.1)	2 (2.4)	2(1.7)	5 (6.5)
Some college	5(17.9)	7 (8.3)	9 (7.4)	6 (7.8)
College graduate	13(46.4)	35(41.7)	55 (45.5)	27(35.1)
Master degree	7 (25.0)	30 (35.7)	45 (37.2)	29 (37.7)
Doctoral degree	1 (3.6)	8 (9.5)	10(8.3)	10(13.0)

Note: Data are presented as median (interquartile range) or n (%).

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Table 2

Reasons why women sought care elsewhere.

Reason	All (n = 106)	<30y (n = 12)	30 to < 35 y (n = 33)	35 to < 40 y (n = 44)	40–42 y (n = 17)	P value
Wanted a second opinion	59 (55.7)	8 (66.7)	20 (60.6)	26(59.1)	5 (29.4)	.12
Not happy with my care	43 (40.6)	4(33.3)	15(45.5)	17(38.6)	7(41.2)	.88
Heard good things about another center	29 (27.4)	5(41.7)	8 (24.2)	11(25.0)	5 (29.4)	.65
Moved	15(14.2)	2(16.7)	5(15.2)	7(15.9)	1 (5.9)	.80
Advised to stop treatment	6(5.7)	0 (0.0)	1 (3.0)	4(9.1)	1 (5.9)	.72
Insurance change required a new center	2(1.9)	0 (0.0)	0 (0.0)	2 (4.5)	0 (0.0)	.74
Other	30 (28.3)	4(33.3)	6(18.2)	13(29.5)	7(41.2)	.34

Note:Data presented as n (%). Women could choose more than one response, so totals may sum to more than 100%.

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Table 3

All reasons and most important reason why women did not seek further care.

Reason	All(n = 199)	<30y (n = 16)	30 to < 35 y (n = 51)	35 to <40y (n = 72)	40–42 y (n = 60)	P value
Further treatment was too stressful						
Any reason	80 (40.2)	2(12.5)	23 (45.1)	35 (48.6)	20 (33.3)	.03
Most important reason	27(14.3)	0 (0.0)	9(19.1)	12(17.1)	6(10.2)	.23
Could not afford out-of-pocket costs						
Any reason	50(25.1)	5(31.3)	6(11.8)	16(22.2)	23 (38.3)	.01
Most important reason	13(6.9)	1 (7.7)	3 (6.4)	2 (2.9)	7(11.9)	.21
Lost insurance coverage						
Any reason	49 (24.6)	5(31.3)	6(11.8)	18(25.0)	20 (33.3)	.06
Most important reason	22(11.6)	1 (7.7)	2 (4.3)	9(12.9)	10(16.9)	.22
Conceived spontaneously						
Any reason	48(24.1)	5(31.3)	17(33.3)	15(20.8)	11 (18.3)	.23
Most important reason	34(18.0)	5 (38.5)	11 (23.4)	11 (15.7)	7(11.9)	.09
Pursuing/have adopted a child						
Any reason	37(18.6)	2(12.5)	7(13.7)	16(22.2)	12 (20.0)	.59
Most important reason	7 (3.7)	1 (7.7)	0 (0.0)	4(5.7)	2 (3.4)	.25
Advised to stop treatment						
Any reason	28(14.1)	1 (6.3)	2 (3.9)	10(13.9)	15(25.0)	.01
Most important reason	13(6.9)	0 (0.0)	0 (0.0)	7(10.0)	6(10.2)	.07
Pursuing/considering child-free living						
Any reason	20(10.1)	0 (0.0)	4 (7.8)	9(12.5)	7(11.7)	.44
Most important reason	3(1.6)	0 (0.0)	1 (2.1)	2 (2.9)	0 (0.0)	.59
Moved to egg or sperm donation						
Any reason	7 (3.5)	0 (0.0)	2 (3.9)	2 (2.8)	3 (5.0)	.94
Most important reason	4(2.1)	0 (0.0)	1 (2.1)	2 (2.9)	1 (1.7)	1.00
Other						
Any reason	77 (38.7)	8 (50.0)	20 (39.2)	25 (34.7)	24 (40.0)	.71
Most important reason	66 (34.9)	5 (38.5)	20 (42.6)	21 (30.0)	20 (33.9)	.56

Note: Data presented as n (%). Total, n = 189; women could choose more than one response, so totals may sum to more than 100%.

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Table 4

Specific sources of stress among women who reported discontinuing treatment because it was too stressful, n (%).

Source of stress	All (n = 80)	<30y (n = 2)	30 to < 35 (n = 23)	y 35 to < 40 y (n = 35)	40–42 y (n = 20)	P value
Had already given IVF my best chance	52 (65.0)	0 (0.0)	14(60.9)	25(71.4)	13(65.0)	.25
Too anxious or depressed to continue	38 (47.5)	2(100.0)	10(43.5)	17(48.6)	9 (45.0)	.63
Infertility was taking too much of a toll on our relationship	29 (36.3)	0 (0.0)	8 (34.8)	12(34.3)	9 (45.0)	.71
Could not stand the side-effects of the medication	24 (30.0)	1 (50.0)	7 (30.4)	10(28.6)	6 (30.0)	.98
Too difficult to get to the IVF center so often	22 (27.5)	2(100.0)	5(21.7)	11(31.4)	4 (20.0)	.13
Could not stand all the side effects of the injections	19(23.8)	1 (50.0)	7 (30.4)	9(25.7)	2 (10.0)	.24
Getting nervous about possible long-term effects of treatment	18(22.5)	2 (100.0)	4(17.4)	6(17.1)	6 (30.0)	.07
Treatment was too expensive	15(18.8)	0 (0.0)	4(17.4)	3 (8.6)	8 (40.0)	.04
Other	26(32.5)	1 (50.0)	4(17.4)	13(37.1)	8 (40.0)	.27

Note: Women could choose more than one response, so totals may sum to more than 100%.

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