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

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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%).
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.)
Key Words: 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

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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 ≥6 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 ≥1 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