

Understanding the perceptions of and emotional barriers to infertility treatment: a survey in four European countries†

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BACKGROUND: Infertility can significantly impact women's lives and personal relationships. Despite the negative impact of infertility, a significant number of women who are struggling to conceive do not consult a physician. This cross-sectional survey was conducted to determine the emotional impact of infertility on women to identify which aspects of fertility treatment contribute to the psychological stress experienced by so many patients and to identify barriers to seeking treatment.

METHODS: Women ($n = 445$; 18–44 years) who had received fertility treatment within the past 2 years or were having trouble conceiving but had not received treatment, completed a 15-min survey online.

RESULTS: Participants were from France ($n = 108$), Germany ($n = 111$), Italy ($n = 112$) and Spain ($n = 114$). Responses indicated that infertility causes a range of emotions and can strain relationships. Women who had received treatment were more likely to feel hopeful (26 versus 21%) and closer to their partner than women not in treatment (33 versus 19%, $P < 0.05$). Most women delayed starting treatment because of a desire to conceive naturally, and on the advice of physicians. Women aged ≥ 35 years took longer to seek help with their fertility issues. Injection-related anxiety was the second greatest barrier to treatment.

CONCLUSIONS: This study has provided insight into the physical and psychological challenges of infertility treatments and permitted a better understanding of the factors that impact patient lives. A treatment protocol with minimal injections and provision of additional information may lessen the emotional impact and challenges of infertility and contribute to patient satisfaction with fertility treatment protocols.

Key words: infertility / psychological / emotional / injection / treatment

Introduction

The inability to conceive a child is extremely stressful for those who hope to start a family. Fertility treatments such as IVF/ICSI provide an opportunity for couples to become parents, with long-term cumulative pregnancy rates nearing 70% (Pinborg *et al.*, 2009). However, the stress associated with infertility can be compounded by IVF treatment, which can be time consuming, strenuous, expensive and frustrating.

The complex psychological impact of infertility on women's lives, personal relationships and family lives has been well documented.

Unsurprisingly, infertility has been associated with depressed mood, anxiety, anger, cognitive impairment and feelings of unattractiveness (Wischmann, 2008; Wilkins *et al.*, 2010; Carter *et al.*, 2011). Women may also be concerned about relationships with their partners and about sexuality (Carter *et al.*, 2011).

Despite the negative impact of infertility on their lives, a significant number of women who are struggling to conceive do not consult a physician. There is evidence that many women decide against consultation because of a fear of being labeled infertile, concerns about lack of family and/or social support and worries about treatment safety

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(Wischmann et al., 2001). Yet, delay in seeking help from a health-care professional, especially in women aged >35 years, increases the risk of remaining childless.

In order to help infertile individuals and couples reduce the psychological burden associated with infertility and treatment, there is a need to know which aspects of infertility pose the greatest difficulties for women. It is crucial to know why infertile women do not seek treatment, what their perceptions of treatment are and how infertility affects their relationships with others. Among women receiving treatment, psychological stress is reported to be the most frequent reason for early discontinuation (Olivius et al., 2004; Rajkhowa et al., 2006; Brandes et al., 2009; Van den Broeck et al., 2009). The negative effects of treatment on a couple's relationship and injection-associated anxiety (Domar et al., 2010) have been shown to be two major causes of stress. Other factors that have been found to lead to patient dropout from treatment are financial burden, a negative impact on social contacts and the perception of a lack of staff expertise (Van den Broeck et al., 2009).

It is not surprising that patients perceive that infertility treatment poses both a physical and psychological challenge. With easy access to information via the plethora of books written by former infertility patients, the thousands of web sites which focus on the rigors of treatment protocols and the stories and complaints of acquaintances, most infertile women are likely to have a negative impression of treatment before ever questioning a physician. Assisted reproduction technology (ART) cycles require multiple injections for weeks, frequent blood tests and vaginal ultrasounds, unpredictable invasive procedures which require missing work and often with <50% chance of that cycle producing a healthy baby, and, for some, a large amount of out-of-pocket expenditures.

This study aims to provide insight into the emotional challenges facing infertile women and their perceptions of treatments, and to identify which aspects of ovarian stimulation treatment contribute to the physical and psychological stress experienced by so many patients.

Materials and Methods

This was a cross-sectional online quantitative study involving women from four European countries—France, Germany, Italy and Spain. These four countries were chosen because they have the highest number of ART cycles in the European Union.

Participants

Participant eligibility criteria were ages of 18–44 years and either currently in treatment for infertility, had received fertility treatments in the past 2 years, or were having difficulty becoming pregnant but were not receiving treatment. Institute Review Board approval was not necessary as participation was entirely anonymous and voluntary.

Study design

Women, from a large pool of potential participants maintained by a market research company, were recruited based on the eligibility criteria. Eligible women completed a 15-min survey, in their local language, between 20 October 2009 and 30 October 2009. The survey was custom designed for this study and consisted of 50 closed-ended and contingency questions. The questions were determined by the authors, based on clinical experience. There is no information available about potential participants who did not choose to complete the questionnaire as

enrolment was entirely voluntary, conducted online and there was no contact between any of the investigators and the participants.

The translations were performed as per the standard double-step process; one native in-country linguist translated the survey and then a second native and in-country linguist reviewed and edited the translation. The survey links were tested by a translator as well.

The survey included questions under the headings of screening, risk factors, current treatment situation (with dropdown questions specific to the answers given under the screening section for those who either experienced ART treatment or no treatment), impact of fertility issues on quality of life and relationships, and basic demographics.

Data were collected online using specialist market research expertise (TNS European Access Panels) in the four European countries, with quotas set to achieve 40 treatment respondents per country.

Statistical analysis

Descriptive statistics were prepared for all data with determination of 95% confidence intervals using the SignaStat v3.5 software package. Pre-defined statistical comparisons were performed for those respondents previously/currently receiving treatment versus those not currently receiving treatment and for potential differences between responses by country using appropriate non-parametric tests (χ^2 and Fisher's exact tests). Statistical significance was set at $P < 0.05$.

Results

A total of 445 women from France, Germany, Italy and Spain took part in the study. A total of 160 women were currently undergoing treatment and 285 were not currently receiving any sort of therapy. The average age was 35 years (range 18–44) and more than half of all respondents had tried methods other than IVF to become pregnant (Table 1). All respondents had been trying to become pregnant during the previous 24 months and 16.4% succeeded with the help of fertility treatments. Approximately half of all women self-injected (46.9%), but almost a third of women in France (22.5%), Germany (27.5%) and Spain (27.5%), and nearly half (47.5%) of the Italian women asked their spouse or partner to administer their daily injections.

Psychological impact of infertility and treatment

Nearly a third of all women (32%) reported that they had been concerned about their ability to become pregnant from the time they started trying to conceive. They reported that on average, after 6–12 months of trying to conceive naturally, their concerns peaked. Perhaps assuming that they would become pregnant easily, younger women were more likely to become concerned after only 6 months of trying than were older women.

Overall, infertility resulted in lowering of self-esteem. Forty percent of women described feeling 'embarrassed', and more than half (55%) agreed that they felt 'inadequate as a woman', 'flawed as a woman' (58%) and that they had waited too long to try to become pregnant (58%). Women receiving treatment tended to feel more vulnerable and overwhelmed, and were significantly more likely ($P < 0.05$) to be focusing on trying to cope than those not receiving treatment (Fig. 1).

Most women felt that they had a supportive partner (59%), especially those receiving treatment (63%). Only 24% of women strongly agreed that difficulty in becoming pregnant had resulted in a closer

Table 1 Demographic characteristics of participants surveyed for perceptions of and emotional barriers to treatment for infertility in Europe.

Characteristic	France (n = 108)	Germany (n = 111)	Italy (n = 112)	Spain (n = 114)	All (n = 445)
Mean age, years (SD)	34.5 (5.71)	34.0 (5.54)	35.3 (5.50)	36.3 (4.84)	35.0 (5.45)
Treatment history, n (%)					
Oral medications	37 (34.3)	51 (45.9)	43 (38.4)	36 (31.6)	167 (37.5)
Hormone injections	40 (37.0)	40 (36.0)	40 (35.7)	40 (35.1)	160 (36.0)
Medical procedures ^a	29 (26.9)	32 (28.8)	41 (36.6)	40 (35.1)	142 (31.9)
Complementary medicine ^b	23 (21.3)	46 (41.4)	35 (31.3)	35 (30.7)	139 (31.2)
Other	10 (9.3)	14 (12.6)	6 (5.4)	3 (2.6)	33 (7.4)
None of these	28 (25.9)	19 (17.1)	19 (17.0)	19 (16.7)	85 (19.1)

^aFor example, IVF, intrauterine insemination, egg donation, sperm donation, embryo donation and surrogacy.

^bFor example, dietary supplements, stress reduction and acupuncture.

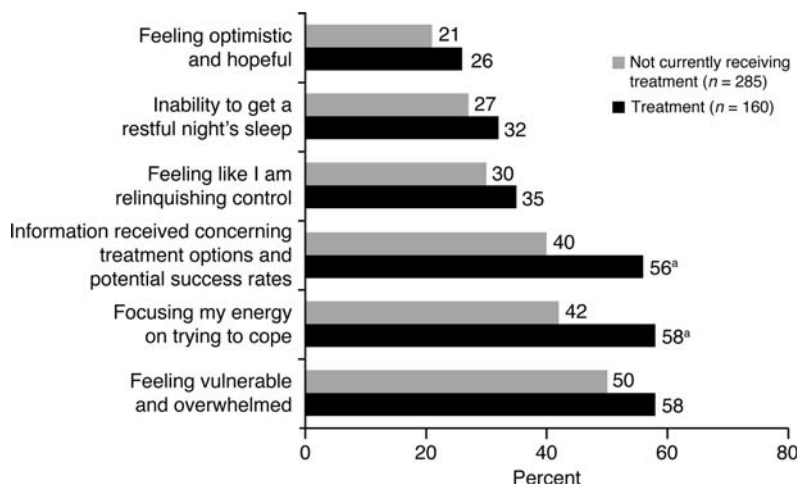


Figure 1 Feelings and behaviors of women in Europe resulting from infertility. ^a $P < 0.05$ versus those not currently in treatment. Appropriate non-parametric tests (χ^2 and Fisher's exact tests) were used to determine statistical significance.

relationship with their partner; however, significantly more women in treatment stated that this was the case (33 versus 19%; $P < 0.05$). Women in treatment reported greater anxiety surrounding sex—they worried that fertility problems had taken the fun and spontaneity out of their sexual relationship.

With respect to extended relationships, almost two-thirds of respondents (288 women) confided in family and friends about their difficulty in becoming pregnant, and the majority (74%) of respondents who did so found them to be supportive. Women receiving treatment were significantly more likely ($P < 0.05$) to believe that they had to constantly explain any progress in the fertility process but that having support systems available made their fertility issues easier to deal with. Many women did, however, report that their difficulty conceiving strained relationships with family and friends. Three-quarters (74%) reported that they felt resentment toward people who took becoming pregnant for granted because it was easy for them. More than half (67%) were tired of being offered suggestions on how to get

pregnant and felt uncomfortable around pregnant women or women with babies (64%).

The emotional impact of infertility and treatment

Women most commonly associated feeling 'hopeful' with infertility treatment (Fig. 2), and this proportion was even greater among women actually in treatment (26 versus 21%; Fig. 1). All women felt 'cautiously optimistic', and a similar proportion felt 'motivated' (Fig. 2). Women who were not yet in treatment were significantly more likely to feel 'reassured' (data not shown).

The most frequently reported negative emotions for all women were those of frustration and impatience (Fig. 2). Women receiving treatment were more likely to feel 'vulnerable' and 'drained', while those not receiving treatment felt more 'confused'. When thinking about treatment involving injections, women had mixed emotions,

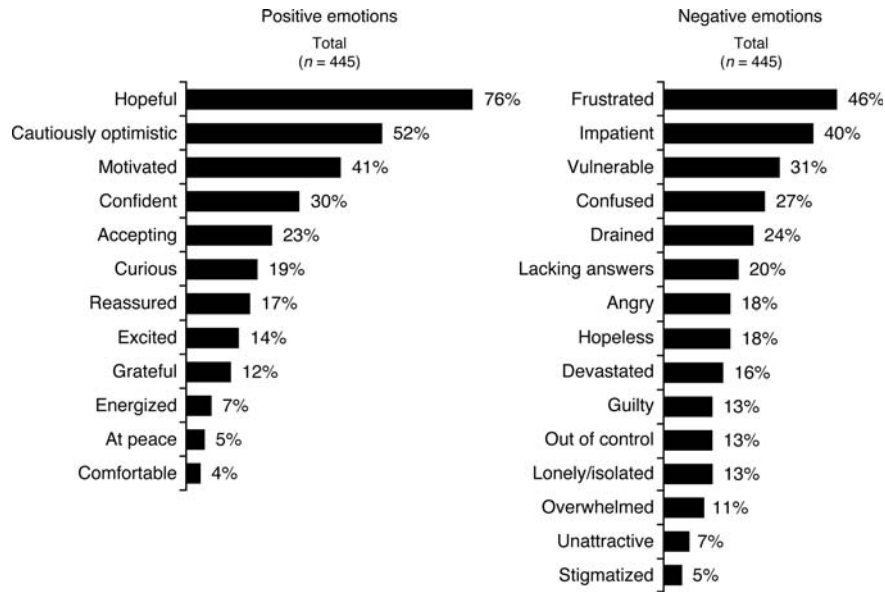


Figure 2 Positive and negative emotions in women associated with infertility and treatment.

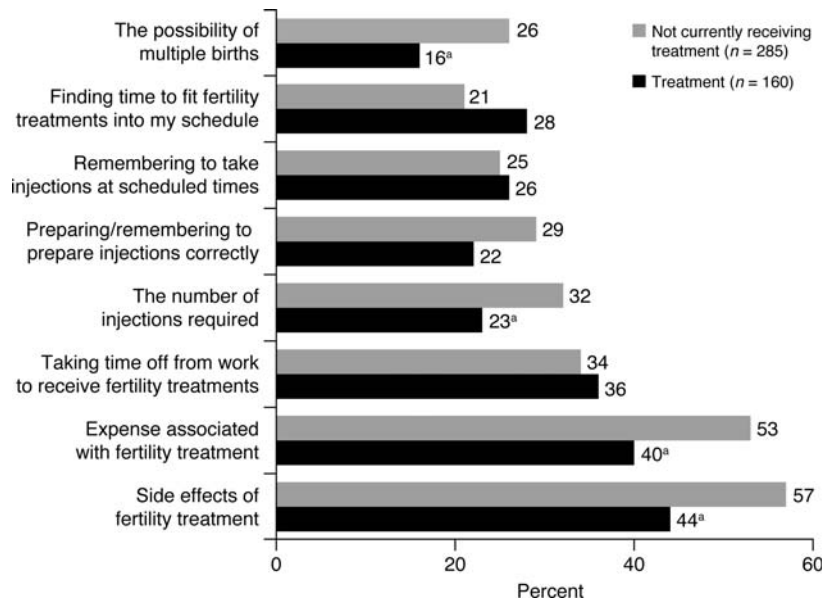


Figure 3 Responses of women regarding perceived functional barriers to injections for treatment of infertility. ^aP < 0.05 versus those not currently in treatment. Appropriate non-parametric tests (χ^2 and Fisher’s exact tests) were used to determine statistical significance.

with most feeling ‘hopeful’ (46%) followed by ‘anxious’ (39%; data not shown). Despite feeling frustrated and impatient, few women turned to the different strategies commonly associated with decreasing stress, which included meditating/yoga, reducing working hours, counselling/support groups and acupuncture (62% ‘none of these’).

Barriers to seeking fertility treatment

Patient concerns regarding fertility treatments

Although the greatest barrier to treatment is emotional, women also have concerns about functional issues, such as the injection process, the possibility of multiple births, time scheduling, cost implications

and side effects (Fig. 3). Fear of failure was the most important emotional barrier to treatment, with the majority (72%) citing 'being upset if treatments don't work' as a major concern. Forty-four percent of women also reported anxiety surrounding administering their own injections or having their injections given by their partner. Side effects of treatment were the main source of concern for half of women, followed by the high cost of treatment. Women not receiving treatment were significantly more likely than those receiving treatment to cite side effects, expense, number of injections and the possibility of multiple births as major concerns (Fig. 3).

Just over half (56%) of the women surveyed started injections once they accepted their fertility challenges (i.e. 'I wasn't going to get pregnant on my own') and 31% began treatment when they became 'concerned about their age and felt time was running out'. More than half (53%) of women preferred to have someone else administer their daily injections (31% partners and 22% health-care professionals) because they feared self-injecting. Only 29% of women in treatment indicated that having a doctor or nurse administer the first injection or two would have reduced their concerns about the injection process. For most women already receiving treatment, a self-injection option that involved fewer injections and more days without injections would have had no impact on their likelihood to start treatment earlier; however, it may have made women who were not in treatment more likely to consider receiving injections earlier. Only 39% of women reported that a treatment option with fewer injections would make it easier to comply with treatment schedules. A third of all women, however, felt that fewer injections would decrease stress levels when calling the doctor's office to verify treatment compliance, although again, half of those in treatment felt it would make no difference.

Initiation of infertility treatment

More than half of the women surveyed (58%) thought they may have waited too long to try to become pregnant. They delayed initiating fertility treatments to give themselves more time to become pregnant naturally, either as a personal decision (38%) or following a doctor's recommendation (27%). On average, women waited for more than a year to talk to a health-care professional, and almost another year (10.6 months) to start injection treatments. Most notably, women aged 35 years and older took longer to seek help with their fertility issues, often waiting 15 months instead of the medically recommended 6 months. Despite the majority (90%) of those surveyed recognizing age as a risk factor, 68% did not think they would have difficulty becoming pregnant when they wanted. Furthermore, of those women who saw a fertility specialist, 81% would have begun treatment sooner if they could repeat the experience.

Effect of work on infertility treatment

The majority of women surveyed worked outside of the home (83%). One-quarter of women receiving treatment (24%) reported that their work schedule had interfered with treatment but on the whole women felt that work did not impact their plans or ability to start a family.

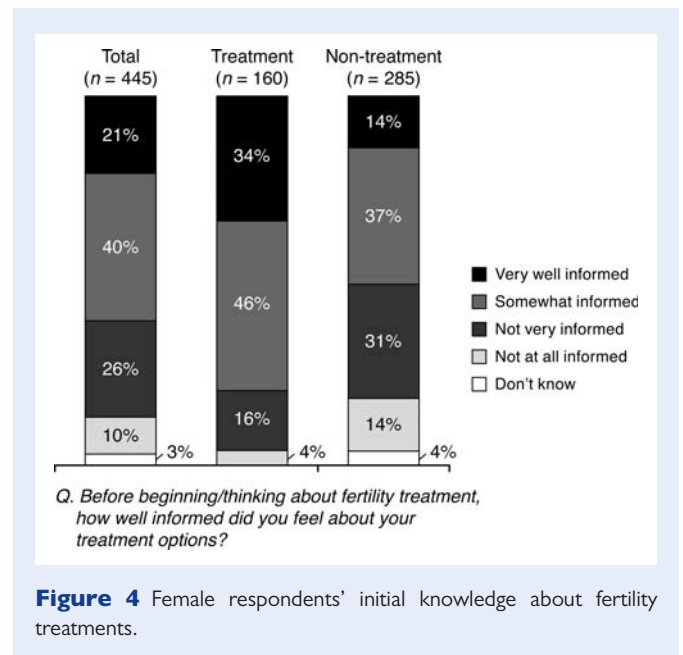


Figure 4 Female respondents' initial knowledge about fertility treatments.

Awareness and knowledge among participants

Most women (40%) reported that they felt only 'somewhat informed' about fertility treatments prior to starting treatment (Fig. 4). Women also reported feeling 'not very informed' about treatment options. Among women receiving treatment, additional information about the risk of side effects (48%) was more often requested than information on cost reimbursement (41%), number of treatments needed (42%), time commitment (34%) or number of injections (33%; data not shown). In addition, 46% of women in treatment would have appreciated more information regarding the emotions they would experience. In general, women not receiving treatment had a greater need for information, specifically regarding financial assistance (56%), time commitment of treatment (46%) and number of injections (44%). The Internet is an increasingly important source of information about fertility treatments; three-quarters (76%) of women receiving treatment had researched their options online. Only 37% of respondents in treatment talked to others who had received treatments.

Discussion

The results of this European study, which takes into account the experiences of women from France, Germany, Italy and Spain, more clearly define the demands of treatment for infertility. Hopefully this information will lead to interventions designed to educate and reassure women who are not yet in treatment and may contribute to patients being more amenable to starting, and more comfortable with, fertility treatment protocols.

The impact of infertility is multifaceted, causing a range of emotions but largely negatively affecting key areas of women's lives. Treatment is stressful and can cause relationship difficulties for couples. Women are also known to be anxious about the injection process (Domar *et al.*, 2010). These major causes of stress can lead to high numbers of patients dropping out of treatment. Women reported feeling

embarrassed and inadequate, and perceived themselves as being flawed. Despite reporting that undergoing fertility treatment increased stress in certain aspects of their relationships with partners, family and friends, women in treatment reported that they received more support from family and friends and that they became closer to their partner than women who were not in treatment. The survey also indicated that women undergoing treatment were more likely to feel hopeful and less concerned about many aspects of therapy, such as treatment side effects, the number of injections required and the possibility of multiple births.

Most women participating in the survey did not begin treatment until 2 years after they started trying to become pregnant, and the majority wish that they had seen a fertility specialist sooner. The desire to wait and see whether pregnancy would occur naturally was the major cause of delay in starting treatment. This delay was most remarkable in women aged >35 years who, despite recognizing that advancing age could seriously impact their ability to conceive, still delayed seeking medical assistance. In retrospect, women reported that this treatment delay caused anxiety and was often regretted.

The psychological impact of infertility treatment is high, and one contributor is that the outcome is uncertain. Therefore, unsurprisingly, fear of failure was the most important barrier to treatment for infertility. Anxiety related to the strict daily injection regimen was the second most important reason for delaying treatment. Changes to the number of injections administered could make the experience more positive for about one-third of women. This finding is consistent with the scientific literature, which indicates that the daily injection schedule places considerable constraints on work, family and social lives (Klonoff-Cohen and Natarajan, 2004; Benyamini et al., 2005; Brod et al., 2007; Brod et al., 2009), and adds to emotional distress (Benyamini et al., 2005).

Fertility experts are becoming increasingly aware of the importance of providing more patient-friendly treatment protocols (such as less complicated treatment regimens with fewer injections) to improve patient well-being and reduce the stress and burden associated with treatment (Nargund and Frydman, 2007; Pennings and Ombelet, 2007; Verberg et al., 2008; Devroey et al., 2009). This is gaining importance in light of an increasing number of reports in the literature that have linked stress to negative treatment outcome (Terzioglu, 2001; Klonoff-Cohen and Natarajan, 2004; Cousineau and Domar, 2007). In contrast to these reports, a recent meta-analysis (Boivin et al., 2011) concluded that emotional distress caused by infertility does not compromise the chance of becoming pregnant. These conflicting findings highlight the complex relationship between distress and IVF outcome, and at present it is difficult to draw any firm conclusions.

These results demonstrate a need for educational interventions to address patient fears, and to better prepare patients for the demands of treatment and the emotions that they may experience. Educating patients about options for treatment may help them seek treatment sooner and therefore lessen the emotional impact and challenges of infertility.

The issue of age is a delicate one. Although fecundity declines with age, many women are unaware of the relationship, fail to understand when that decline begins, or have the impression that their own good health habits and youthful appearance somehow protect their eggs from aging. Although it is well established that ART success rates fall in accordance with the age of the egg, in this survey 68% of the

women >35 years did not think they would have issues conceiving. It is notable that once they saw a fertility specialist, 81% wish they had seen one sooner. Conversely, scaring women into pursuing treatment prior to it being needed should not be the goal. Encouraging IVF too early has costs as well, including side effects of treatment, the financial cost and the risk of multiple births (Habbema et al., 2009). Widely promoting the current guidelines of seeking out a medical consult based upon the woman's age seems to be a wise solution.

Improving the quality of information available to patients has been demonstrated to be one of the easiest ways to improve patient experiences (Dancet et al., 2010; Bunge et al., 2010). Checklists and fertility treatment questionnaires can be used by health-care professionals to address patient concerns (Klonoff-Cohen and Natarajan, 2004). Even developing educational materials together with the patients themselves has also been shown to be beneficial (Pook and Krause, 2005). Information should be in line with what is required at each stage of treatment, as too much information can minimize the benefits of educational materials (Takefman et al., 1990). Patient education should also address concerns about side effects, cost of treatment and the possibility of multiple births, as these issues were found to weigh on patients' minds.

This study provides valuable insight into the aspects of infertility treatment that are of the greatest concern to women. However, there are some possible limitations to the study design. Owing to the questionnaire format of the study, women who had a more negative experience may have chosen to participate more readily in order to vent their feelings than those women who were less emotional about their experiences of IVF. This could result in a selection bias in the type of subjects recruited. Conversely, the online study design could make the questionnaire more approachable, with women more able to express themselves. A second limitation could be recall bias, because a proportion of the women would have been reporting on the impact of treatment a while after their experience. Finally, it is possible that participants are utilizing coping strategies, which were not included in the survey; future research should include a specific measure for coping strategies.

In conclusion, this study has provided further insight into the burden of infertility treatments and permitted a better understanding of the factors that impact on patients' lives. Many of these issues could be addressed in part with additional patient education but there is a need for more patient-friendly treatment regimens to help reduce the physical demands of treatment and minimize disruptions to daily activities.

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Authors' roles

A.D. and K.G. contributed to the design of the survey, participated in the interpretation of the data and drafted the paper. K.G. also contributed to data collection and management. J.G.-V., A.L.M., P.B. and F.B. interpreted the data and revised the paper critically for important

intellectual content. All authors gave final approval of the version to be published.

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Conflict of interest

F.B. and K.G. are employed by MSD, Italy. A.D. is recipient of a grant from Merck and has received payments for lectures from Merck but both relationships are completely non-branded and do not involve any product.

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