

## ARTICLE

# Barriers and factors associated with significant delays to initial consultation and treatment for infertile patients and partners of infertile patients



## BIOGRAPHY

Alice Domar, PhD, is the Executive Director of the Domar Centers for Mind/Body Health, Director of Integrative Care at Boston IVF, and part-time Associate Professor of Obstetrics, Gynecology, and Reproductive Biology, Harvard Medical School, USA. She is the author of seven books and co-creator of the apps FertiCalm and FertiStrong.

Alice Domar<sup>1,\*</sup>, Rita Vassena<sup>2</sup>, Marjorie Dixon<sup>3</sup>, Mauro Costa<sup>4</sup>, Elena Vegni<sup>5</sup>, Barbara Collura<sup>6</sup>, Marie Markert<sup>7</sup>, Carl Samuelsen<sup>7</sup>, Jillian Guiglotto<sup>8</sup>, Eva Roitmann<sup>9</sup>, Jacky Boivin<sup>10</sup>

## KEY MESSAGE

An average 3-year wait before infertility diagnosis indicates reduced chances of success due to older age. Patient-provider relationships and supportive service offerings were significantly associated with treatment initiation, highlighting the importance of communication and service quality. Partners showed a high concurrence with patients regarding the significance of supportive service offerings.

## ABSTRACT

**Research question:** What are the key drivers and barriers for infertile patients and their partners to see an infertility specialist and initiate treatment?

**Design:** An online, international, 30-minute quantitative survey collected data from 1944 respondents from nine countries. Respondents were infertile patients ( $n = 1037$ ) or partners of infertile patients ( $n = 907$ ; but not necessarily partners of the patient sample), at different stages of the treatment journey.

**Results:** The overall average times were 3.2 years to receiving a medical infertility diagnosis, 2.0 years attempting to achieve pregnancy without assistance before treatment, and 1.6 years of treatment before successful respondents achieved

<sup>1</sup> Boston IVF, Domar Center for Mind/Body Health, Waltham, MA and Harvard Medical School, Boston MA, USA

<sup>2</sup> Clinica EUGIN Barcelona, Spain

<sup>3</sup> ANOVA Fertility and Reproductive Health, University of Toronto, Toronto ON, Canada

<sup>4</sup> Reproductive Medicine, International Evangelical Hospital, Genova, Italy

<sup>5</sup> Department of Health Sciences, Università Statale di Milano, Milan, Italy

<sup>6</sup> RESOLVE: The National Infertility Association, McClean, Virginia, USA

<sup>7</sup> Ferring Pharmaceuticals, Health Economics & Outcomes Research, Copenhagen, Denmark

<sup>8</sup> W2O Group, Integrated Intelligence, Philadelphia PA, USA

<sup>9</sup> Roitmann Digsmed SASU, Paris, France

<sup>10</sup> School of Psychology, Cardiff University, Cardiff, UK

## KEYWORDS

Infertility treatment  
Partner perspective  
Patient perspective  
Survey  
Treatment delay  
Treatment journey

pregnancy. The most common driver for considering treatment after a consultation ( $n = 1025$ ) was an equal desire within the couple to have a child (40.8%). Of the partners ( $n = 356$ ), 29.8% reported that transparency of information from healthcare professionals about treatment expectations was important. A significantly higher proportion of respondents seeking treatment reported that healthcare professionals offered supportive services (61.2%) and mental health services (62.0%), than of the 207 respondents who did not seek treatment (32.4% and 36.7%, respectively;  $P < 0.001$ ). Perceived cost was the most commonly reported barrier for respondents not seeking a consultation (37.5% of  $n = 352$ ) or treatment (42.0% of  $n = 207$ ). Of the 95 respondents who discontinued treatment, 34.7% discontinued due to the financial impact.

**Conclusions:** Respondents reported significant delays to seeking treatment, probably negatively impacting the chances of achieving pregnancy. Motivational coherence within couples was a key driver and cost of treatment was the main barrier. Reported supportive service offerings by healthcare professionals were significantly associated with continuation of the treatment journey.

## INTRODUCTION

Approximately 8–12% of couples worldwide experience difficulties achieving pregnancy, and this rises to 1 in 4 couples in developing countries (Boivin *et al.*, 2007; Kumar and Singh, 2015; World Health Organization 2004). Some regions experience a particularly high infertility prevalence, including areas of Europe, Asia and Africa (Inhorn and Patrizio, 2015). Infertility is defined as the failure to achieve a clinical pregnancy after at least 12 months of regular, unprotected sexual intercourse (Zegers-Hochschild *et al.*, 2009). This condition is becoming increasingly common, probably in part due to the modern trend to pursue educational goals and economic stability prior to starting a family, therefore delaying pregnancy until older age (Molina-García *et al.*, 2019; Lemoine and Ravitsky, 2015)

Current literature has suggested that parenthood is considered to be central to the life plan of most adults (Boivin *et al.*, 2018). Both men and women can feel an intense and profound desire for parenthood, indicating an emotional engagement acting as a driving force for patients to seek treatment for infertility (Hadley and Hanley, 2011; Langher *et al.*, 2019). With the availability of reproductive technologies and treatment processes, it has been suggested that increased social pressure might be a significant driver to seek treatment and achieve pregnancy (Langher *et al.*, 2019). A further important factor in determining patient treatment decisions is communication with the healthcare provider (HCP) team through infertility diagnosis, consultation and treatment, as quality of service influences the patients' experiences (Klitzman, 2018).

There are challenges encountered by both patients and their partners

throughout the treatment journey, from the initial consultation to receiving treatment. Perhaps the most well established barrier to treatment for patients is the financial impact of the process, a particular issue in developing countries (Dyer and Patel, 2012; Eisenberg *et al.*, 2010; Wu *et al.*, 2013). Studies have demonstrated that wealthier patients, particularly those with a household income of over \$100,000, are more likely to utilize infertility services (Chandra *et al.*, 2014; Smith *et al.*, 2011). Therefore, cost can significantly impact the accessibility, and use of, fertility treatments (Klitzman, 2017).

However, cost is not always the main barrier to treatment; even in countries where fertility treatment is covered by national health policies, patients often fail to initiate treatment after a consultation or discontinue treatment before achieving their goals (Brandes *et al.*, 2009; Jain and Hornstein, 2005). Further challenges to continuing the treatment journey include concerns about the emotional and physical impact of treatment (Eisenberg *et al.*, 2010; Gameiro *et al.*, 2012). In countries where the standard three-cycle treatment regimen is offered, a systematic literature review found that 22% of patients who do not achieve pregnancy do not complete all three cycles (Gameiro *et al.*, 2013a). In circumstances where public funding is available for more than three cycles, discontinuation rates can reach 70% (Brandes *et al.*, 2009).

There is increasing attention surrounding the time taken to achieve pregnancy for infertile couples and how best to incorporate the need for multiple cycles of treatment in patient consultations (Harrison *et al.*, 2021; Sunkara *et al.*, 2020). There is currently little research into the time taken to receive a medical infertility diagnosis, although it is understood that delays to receiving

a medical diagnosis of infertility specifically caused by endometriosis are significant (Ballard *et al.*, 2006; Santos *et al.*, 2012). Therefore, there is a need to better understand the length and cause of delays throughout the treatment journey (Schmidt *et al.*, 2012). Greater understanding would allow the deployment of interventions to minimize the delay, and therefore reduce the impact of age-related fertility decline on treatment outcomes (ASRM, 2012). This would ultimately allow the optimization of time to pregnancy and potentially improve clinical and well-being outcomes. Additionally, the majority of research considers only female patients, neglecting to examine the perspectives of male patients or the partners of patients considering fertility treatment. The aim of this study was to describe the delays, key drivers and barriers to seeking a consultation and subsequently undergoing and continuing fertility treatment for patients and partners.

## MATERIALS AND METHODS

### Study design

This study used a quantitative questionnaire to explore the delays, drivers and barriers within the infertility journey for infertile patients and partners of infertile patients. A targeted literature review was conducted to explore the understanding of fertility in addition to treatment choices and persistence for infertile couples. This informed the development of an international, 30-minute, online survey for this study. The survey was developed in English and translated into French, German, Italian, Spanish and Mandarin. Translations were validated by national linguists. Data were collected from 15 March to 17 May 2019 and responses were anonymized.

The target for recruitment was 1980 respondents overall, including 110 infertile

patients and 110 partners of infertile patients (but not necessarily partners of the patient sample) from each of the nine countries (USA, Canada, UK, France, Germany, Italy, Spain, Australia and China). Both men and women were recruited as patients and as partners of infertile patients.

All respondents who were included in this study were required to have directly received a medical infertility diagnosis at a medical consultation (patient) or to be a partner of someone who had received a medical diagnosis of infertility (partner). Treatments for respondents who had received at least one treatment cycle included assisted reproductive technology (ART), intrauterine insemination or donor gametes. There were further sub-quotas to ensure the inclusion of respondents who received an infertility diagnosis at a medical consultation (self-reported) but did not explore a consultation, respondents who had attended a consultation to discuss treatment options but decided not to enrol in treatment, respondents who had been successful in fertility treatment and respondents who had been unsuccessful after at least two treatment cycles. This ensured that respondents were recruited from different stages of the treatment journey.

Respondents were identified through data collection partner M3 Global Research and were sent an email inviting them to participate in the survey. This alerted the respondent to the general topic of the survey, duration and honorarium amount, and provided additional guidance on what was required. Respondents were informed that responses were confidential and provided in aggregate. All e-mail invitations complied with both ISO 20252 (Market Research Standards) and ISO 27001 (Information Security Standards) guidelines.

The respondent screener was incorporated at the start of the survey to ensure that only respondents who met the screening criteria were included. To be eligible, respondents needed to have received, or have a partner who had received, a medical infertility diagnosis while under the age of 50 years and had had received infertility treatment within the last 5 years (see Supplementary Materials for the full respondent screener). An honorarium was provided

to respondents who completed the full survey, compliant with relevant guidelines.

Respondents were asked to record the time spent trying to achieve pregnancy without assistance before receiving an infertility diagnosis at a medical consultation, the time spent trying to achieve pregnancy without assistance from receiving a medical infertility diagnosis to enrolment in treatment, and the time spent receiving fertility treatment before pregnancy. Respondents completed time estimates up to the stage within the infertility journey from which they were recruited (after receiving a medical infertility diagnosis, after receiving a medical consultation to discuss treatment options, or after receiving treatment). The next section of the survey captured information on reasons for respondents choosing to seek treatment, including interactions with their HCP team. Respondents were then asked to select barriers that they had experienced in seeking, and continuing with, treatment. When reporting drivers and barriers to treatment, respondents selected their responses from a list of prespecified answers.

Ethical approval was not required for this survey study as per the EphMRA code of conduct (*EphMRA, 2017*).

## Statistical analysis

Statistical analyses were performed on the data to explore potential relationships between responses to questions. The first of these was to explore any associations between drivers to seek treatment and between barriers to seeking consultation and treatment using Cramér's V analyses. Chi-squared tests were used to determine which responses were more often barriers than drivers and which were more often drivers than barriers. Finally, a chi-squared analysis was used to explore differences between patients and partners in responses to drivers and barriers.

## RESULTS

### Patient characteristics

A total of 1944 respondents met the extensive screening criteria necessary to take part in the survey and be included in this study (see [TABLE 1](#) and Supplementary Table S1 in the supplementary information for baseline characteristics for all countries). Data were collected from 1037 infertile patients and 907 partners of infertile patients (not necessarily partners of the patient sample). The number of respondents at each stage within the infertility journey can be seen in [FIGURE 1](#).

For the overall respondent population, the average age was 35.8 years (standard deviation [SD] = 9.7) and most were

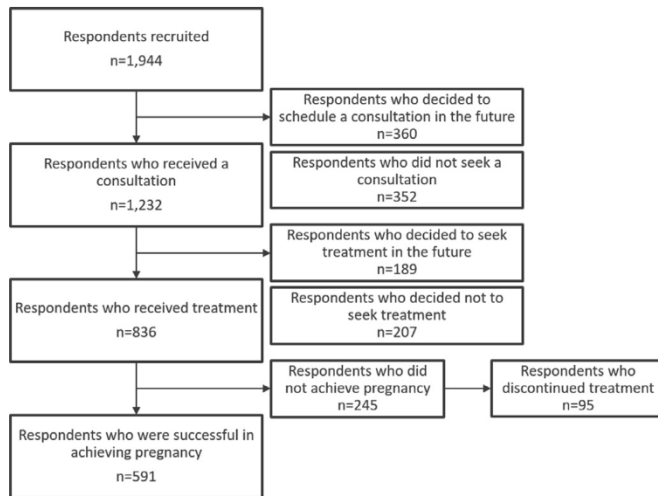
**TABLE 1 BASELINE CHARACTERISTICS OF OVERALL RESPONDENTS, PATIENTS AND PARTNERS**

Patient characteristic	All	Patients	Partners <sup>a</sup>
Average age, years (SD)	35.8 (9.7)	35.0 (8.7)	36.6 (10.6)
Sex			
Male	43.6	33.8	54.7
Female	56.3	66.1	45.2
Sexual preference			
Heterosexual	91.2	90.5	92.1
Homosexual	5.9	6.6	5.1
Other	2.9	3.0	2.9
Marital status			
Single	22.5	18.3	26.6
Married	66.7	72.0	61.6
Divorced	4.4	4.1	4.6
Widowed	1.1	0.9	1.3
Other	5.4	4.7	6.0

The study groups included 1037 patients and 907 partners (total = 1944), except for marital status, which included 822 patients and 855 partners (total = 1677).

Data are percentages unless otherwise indicated.

<sup>a</sup> Partners were not necessarily partners of the patient sample.



**FIGURE 1** Flow diagram to show the number of respondents who sought consultation and treatment and achieved pregnancy.

female (56.3%;  $n = 1095$ ). Most respondents were heterosexual (91.2%;  $n = 1773$ ), and over half were married (66.7% of those asked this question;  $n = 1119$ ). Most patients were women and most partners were men. Medical infertility-related diagnoses that either respondents or their partners had received at a medical consultation are also reported. Treatment funding

sources were investigated (TABLE 2), with the highest proportion of respondents reporting coverage by private health insurance (51.8%;  $n = 387$ ).

#### Average time to medical infertility diagnosis, treatment, pregnancy

All the survey respondents ( $n = 1944$ ) reported the time they spent trying to achieve pregnancy without assistance

before receiving an infertility diagnosis at a medical consultation, and the time spent trying to achieve pregnancy without assistance from receiving a medical infertility diagnosis to enrolment of treatment. Respondents who achieved pregnancy ( $n = 591$ ) also reported the time from treatment initiation to pregnancy. These outcomes are presented in TABLE 3 and FIGURE 2.

The overall average time spent trying to achieve pregnancy without assistance before receiving a medical infertility diagnosis for all respondents ( $n = 1944$ ) was 38.6 months (SD = 28.9). Analysis by country revealed that the longest average time to receiving a medical infertility diagnosis was reported by respondents in the USA (41.9 months; SD = 32.8). Time to receiving a medical infertility diagnosis in European countries varied, from 41.6 months (SD = 33.8) in France to 33.5 months (SD = 21.3) in Spain. Respondents in China reported the lowest overall average time to receiving a medical infertility diagnosis (32.2 months; SD = 22.2).

After receiving a medical infertility diagnosis, the average time spent trying

**TABLE 2** TREATMENT COVERAGE/FUNDING THROUGH HEALTH INSURANCE FOR OVERALL RESPONDENTS, PATIENTS AND PARTNERS WHO CHOSE TO UNDERGO TREATMENT

Treatment coverage/funding through health insurance	All ( $n = 747$ )	Patient ( $n = 490$ )	Partner ( $n = 257$ ) <sup>a</sup>
[My/my partner's] treatment(s) were covered/funded through private health insurance	51.8	51.8	51.8
[My/my partner's] treatment(s) were covered/funded through public health insurance	35.3	36.3	33.5
[My/my partner's] treatment(s) were NOT covered/funded through health insurance	20.1	18.8	22.6
Unknown/unsure	1.1	0.6	2.0

Data are percentage values.

Respondents were able to report both public and private coverage and thus the columns in the table do not sum to 100%.

Respondents who reported coverage/funding through health insurance did not necessarily have 100% coverage.

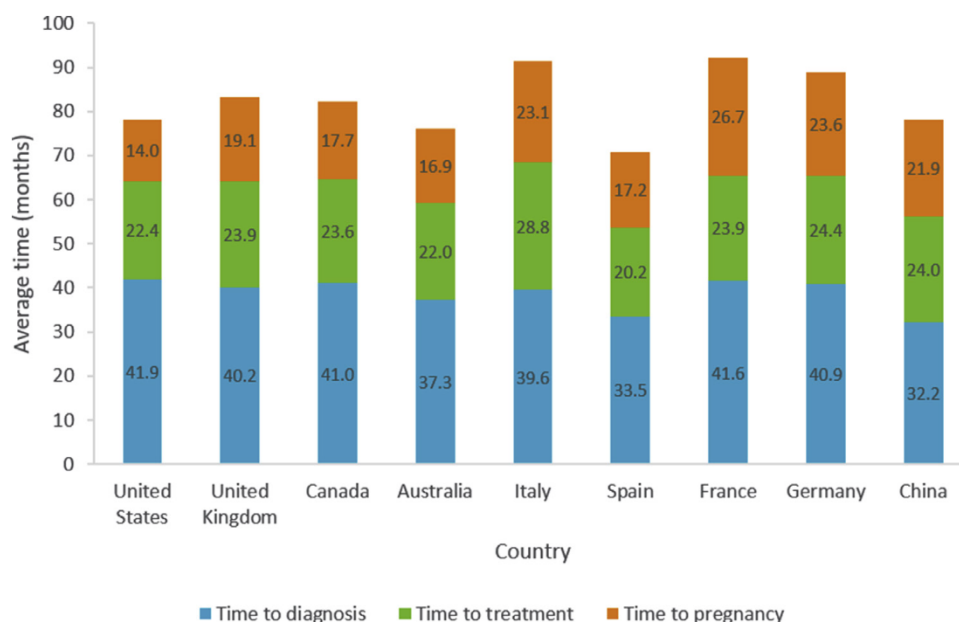
<sup>a</sup> Partners were not necessarily partners of the patient sample.

**TABLE 3** AVERAGE TIME TO INFERTILITY DIAGNOSIS, TREATMENT AND PREGNANCY FOR OVERALL RESPONDENTS, PATIENTS AND PARTNERS

Treatment journey stage	Average time to event/months					
	All ( $n = 1944$ )		Patients ( $n = 1037$ )		Partners ( $n = 907$ ) <sup>a</sup>	
	Mean (SD)	Median (range)	Mean (SD)	Median (range)	Mean (SD)	Median (range)
Trying to achieve pregnancy without assistance prior to infertility diagnosis	38.6 (28.9)	30 (0–191)	40.5 (29.8)	34 (0–191)	36.5 (27.7)	28 (0–191)
Trying to achieve pregnancy without assistance after infertility diagnosis, but before any treatment was initiated	23.6 (25.7)	17 (0–191)	24.6 (27.3)	17 (0–191)	22.4 (23.8)	15 (0–180)
Receiving treatment prior to achieving pregnancy	19.6 (16.3)	14 (0–145)	19.8 (16.7)	14 (0–145)	19.1 (15.4)	14 (1–96)

The study groups included 1037 patients and 907 partners (total = 1944), except for 'Receiving treatment prior to achieving pregnancy', which included 405 patients and 186 partners (total = 591).

<sup>a</sup> Partners were not necessarily partners of the patient sample.



**FIGURE 2** Average time to diagnosis, treatment and pregnancy for overall respondents by country.

to achieve pregnancy without assistance before the initiation of fertility treatment for all respondents ( $n = 1944$ ) was 23.6 months ( $SD = 25.7$ ). There were small variations by country. The shortest average time was observed in Spain (20.2 months;  $SD = 19.8$ ) and the longest average time was reported in Italy (28.8 months;  $SD = 29.7$ ).

After the initiation of treatment, 591 respondents reported the length of time for which they received treatment before they achieved pregnancy. The average time reported was 19.6 months ( $SD = 16.3$ ). Analysis by country showed that respondents in the USA reported the shortest average time (14.0 months;  $SD = 11.6$ ) and the longest average time was observed in France (26.7 months;  $SD = 20.2$ ).

### Drivers to seek consultation and treatment

Following the receipt of a medical infertility diagnosis, 63.4% of respondents ( $n = 1232$ ) had a consultation to explore treatment options. There were 1025 respondents who then had either begun treatment or planned to initiate treatment in the future. These respondents were asked to report their motivations for seeking treatment (see Supplementary Table S2 in the supplementary information). The most frequent response was "My partner and I were equally keen to have a child by any means necessary", reported by 40.8% ( $n = 418$ ) of

respondents. This statement was the most commonly reported driver across five of the nine countries (USA, UK, Canada, Australia and Germany). Respondents from the remaining countries most frequently reported "The timing was right", "I was determined to try anything to be a parent" and "[I/My partner] had great support from [my partner/me]". The second most common driver overall was "I was determined to try anything to be a parent", reported by 38.4% ( $n = 394$ ) of respondents. Cramér's V analyses showed that these responses were strongly associated and therefore often reported together (Cramér's  $V = 0.30$ ). Transparency from the HCP team about treatment expectations was also important to both patients (24.4%;  $n = 163$ ) and partners (29.8%;  $n = 106$ ).

The prespecified responses for drivers and barriers to consultation and treatment were approximate opposites. For example, the "equal" desire within a couple to achieve pregnancy could be selected as a driver ("My partner and I were equally keen to have a child by any means necessary") or a barrier ("My partner and I were not equally keen to have a child by any means necessary"). Chi-squared analyses explored the frequency with which responses were selected for both questions and found that the two most commonly reported drivers to seek treatment, "I was determined to try anything to be a parent" and "My partner and I were equally keen to have a child

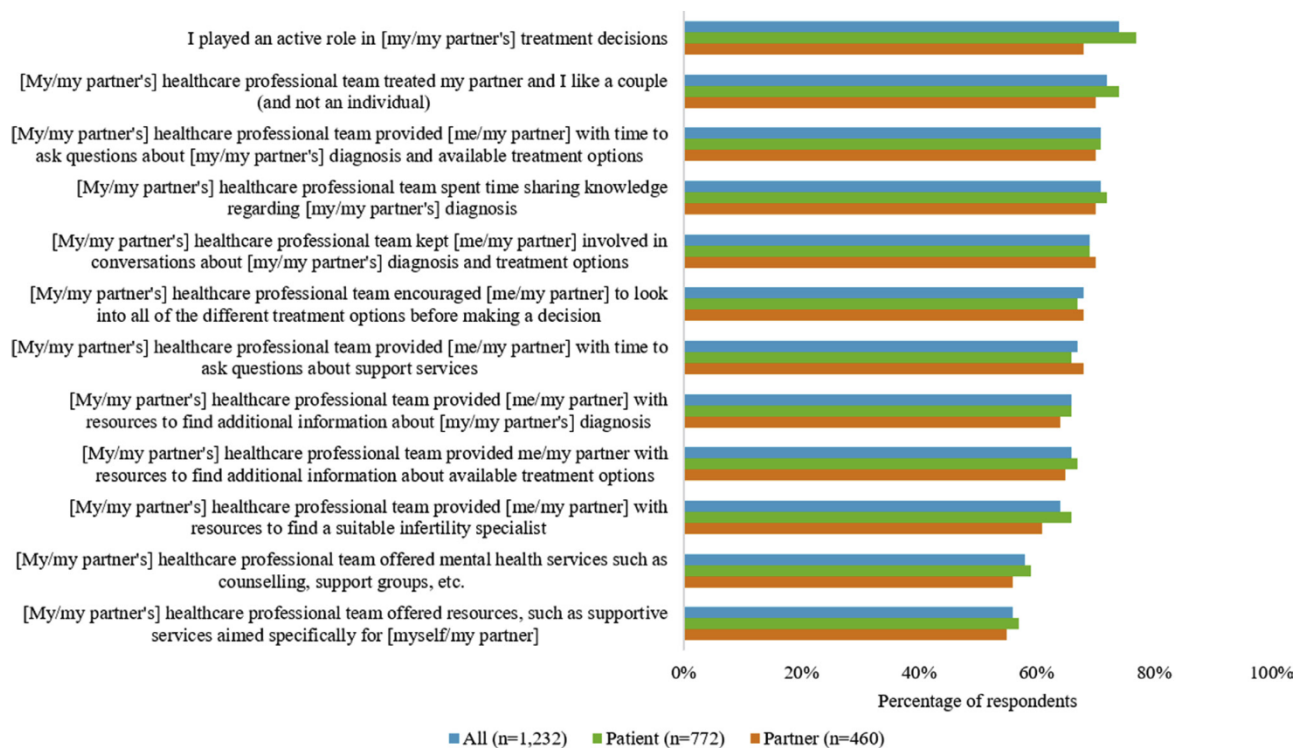
by any means necessary", were reported more frequently as drivers than barriers ( $P < 0.0001$ ).

Further chi-squared analyses revealed that more patients reported "My partner and I were equally keen to have a child by any means necessary" and "I was determined to try anything to be a parent" than statistically calculated expected frequencies ( $P = 0.01$  and  $P = 0.02$ , respectively). For partners of infertile patients, chi-squared showed that answers related to "support" in the relationship were more commonly selected as drivers than statistically calculated expected frequencies ( $P = 0.03$ ).

There were 472 respondents who decided to proceed with further fertility treatments after at least one failed attempt (see Supplementary Table S3 in the supplementary information). The most common driver to continue was "My partner and I were equally keen to have a child by any means necessary", reported by 37.9% ( $n = 179$ ) of respondents. This statement was the most frequently reported statement in six of the nine countries and in both patient and partner subgroups.

### Communication within relationships and with the HCP team

Respondents who had received a consultation ( $n = 1232$ ) were asked to rank statements relating to treatment decisions and the role of the HCP team.



**FIGURE 3** Percentage of all respondents, patients and partners reporting agreement with statements regarding healthcare provider team engagement. Respondents ranked the statements from 1 (do not agree at all) to 7 (completely agree). The graph shows the percentage of respondents ranking each statement from 5 to 7 on a 7-point scale. Partners were not necessarily partners of the patient sample.

The statement “I played an active role in [my/my partner's] treatment decisions” was the most highly ranked statement overall, and across four of the nine countries. **FIGURE 3** shows the proportion of all respondents, patients and partners of infertile patients reporting “agreement” or “strong agreement” with each statement (rankings of 5–7 on the 7-point scale). The statement “I played an active role in [my/my partner's] treatment decisions” was agreed with most frequently among all respondents, followed by “[My/my partner's] healthcare professional team treated my partner and I like a couple (and not an individual)”. Patients and partners of infertile patients generally reported similar levels of agreement, although there was some variation in agreement with “I played an active role in [my/my partner's] treatment decisions”, reported by 77.0% of patients and 68.0% of partners.

Further analysis showed variations in perceptions about the HCP team depending on treatment decisions (**FIGURE 4**). Respondents who sought treatment agreed more frequently (reporting 5–7 on the 7-point scale) with all positive statements about their HCP team than those who chose not to seek

treatment. The statement with which respondents most frequently agreed was “[My/my partner's] healthcare professional team treated my partner and I like a couple (and not an individual)”, reported by 76.0% of respondents who sought treatment. A significantly higher proportion of respondents seeking treatment reported that healthcare professionals offered “supportive services” (61.2%) and “mental health services” (62.0%), than of respondents who did not seek treatment (32.4% and 36.7%, respectively;  $P < 0.001$ ).

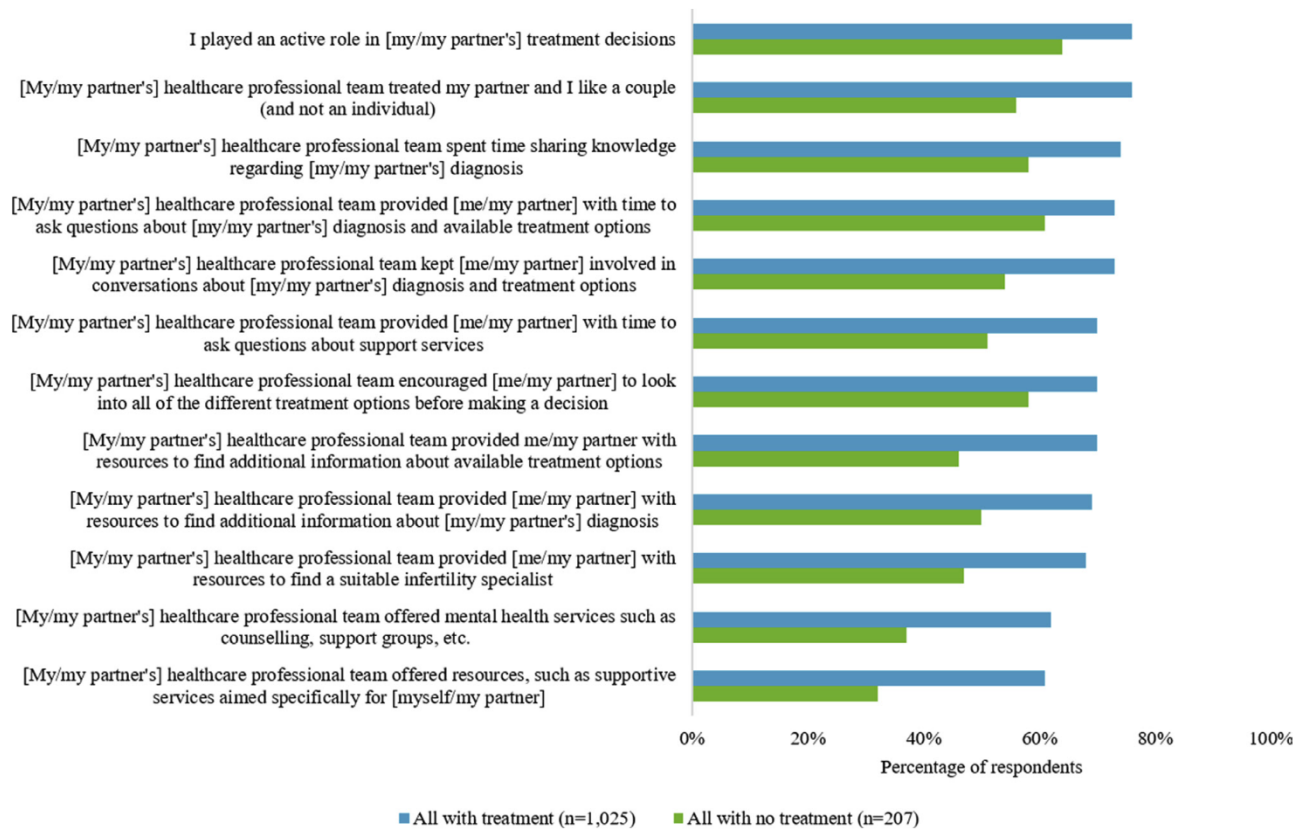
#### Barriers to seeking consultation and treatment

Respondents who discontinued their treatment journey after receiving a medical infertility diagnosis, consultation or initiation of treatment were asked to report the reasons for their decision (see Supplementary Table S4, Table S5 and Table S6). Of those who decided against seeking a consultation to explore treatment options (18.1%;  $n = 352$ ), the most common barrier was “Fertility treatments are costly”, reported by 37.5% ( $n = 132$ ) of respondents. Cramér's V analyses showed that this barrier had a strong association with “[I/my partner] was determined to conceive a child naturally”

and “[I/my partner] could no longer afford the cost of fertility treatments” (Cramér's V for both associations = 0.28), indicating that they were frequently reported together. Chi-squared analyses of the frequency with which statements were selected as drivers and barriers revealed that the cost of treatment was more often reported as a barrier than a driver ( $P < 0.0001$ ), as were concerns about the time investment ( $P < 0.01$ ) and emotional strain ( $P < 0.05$ ).

Of the 1232 respondents who sought a consultation, 207 did not subsequently initiate treatment. The most commonly reported reason for this was “Fertility treatments are costly”, selected by 42.0% ( $n = 87$ ) of all respondents. The second most frequently reported barrier was “[I/my partner] was determined to conceive a child naturally”, reported by 30.9% ( $n = 64$ ) of respondents. Like previous results, there was a strong association between these two statements (Cramér's V = 0.27), and between “Fertility treatments are costly” and “[I/my partner] could no longer afford the cost of fertility treatments” (Cramér's V = 0.28).

Analysis by patient and partner subgroups revealed similar results for respondents



**FIGURE 4** Percentage of respondents reporting agreement with healthcare provider team-related statements, grouped by intention to receive treatment. Respondents ranked statements from 1 (do not agree at all) to 7 (completely agree). The graph shows the percentage of respondents ranking each statement from 5 to 7 on a 7-point scale.

who chose not to seek a consultation and respondents who chose not to initiate treatment. In both populations, a higher proportion of patients were concerned about the cost of fertility treatments (42.3%;  $n = 52$  and 48.5%;  $n = 50$ , respectively) than were partners of infertile patients (34.9%;  $n = 80$  and 35.6%;  $n = 37$ , respectively); however, the difference between patients and partners was not statistically significant in both populations ( $P = 0.21$  and  $P = 0.08$ , respectively). Cost remained the most commonly reported barrier overall.

The greatest disparity between patient and partner responses for respondents who did not seek a consultation was in the statement “[I/my partner] was worried about the physical strain of undergoing treatment”, reported by 23.6% of patients ( $n = 29$ ) and only 10.9% of partners ( $n = 25$ ). Chi-squared analyses revealed that this statement was selected more frequently by patients than statistically calculated expected frequencies ( $P < 0.01$ ). The greatest disparity in patient and partner responses among those who did not initiate treatment was in agreement

with “[I/my partner] was concerned about the side effects of fertility treatments”, reported by 40.8% of patients ( $n = 42$ ) and 18.3% of partners ( $n = 19$ ).

“Fertility treatments are costly” was the greatest barrier to consultation across seven of the nine countries and to treatment initiation in five countries. This statement was reported more frequently by females (43.8%;  $n = 96$ ) than males (27.1%;  $n = 36$ ).

There were 95 respondents who discontinued treatment for reasons other than achieving pregnancy. The most frequently reported reason was “Fertility treatments are costly” (by 34.7% of respondents;  $n = 33$ ), with little variation across patient and partner subgroups. In Canada, 7 of 9 respondents reported cost as a barrier to continuation of treatment, compared with only 1 of 11 respondents in Italy.

## DISCUSSION

Overall, respondents delayed fertility treatment for years, which can

significantly reduce the chances of achieving pregnancy. Motivational coherence within the couple and offers of support from the HCP team were significant determinants of infertility journey continuation. Cost was the main barrier to treatment. These results highlight the importance of support for patients and partners seeking treatment, financial planning and awareness of the impact of delays on treatment outcome.

Respondents took longer than clinically recommended before seeking medical attention and treatment for infertility. There is little research documenting the time to milestones within the infertility journey, but this study suggests significant delays for patients and partners, particularly in receiving a medical infertility diagnosis. Despite the definition of infertility as the failure to achieve pregnancy after 1 year (12 months) of regular, unprotected sexual intercourse, respondents reported an average of 3.2 years (38.6 months) of trying to achieve pregnancy without assistance before receiving a medical infertility diagnosis (Zegers-Hochschild et al.,

2009). The subsequent average 2.0 years (23.6 months) spent trying to achieve pregnancy without assistance before treatment and 1.6 years (19.6 months) receiving treatment before pregnancy resulted in an average overall treatment journey length of 6.8 years.

There are likely to be multiple factors contributing to the length of time before receiving a medical infertility diagnosis, including the established lack of infertility awareness, education level, negative beliefs about the cost, accessibility and safety of treatment, and a fear of receiving a medical infertility diagnosis and being stigmatized (Bunting *et al.*, 2007; Costa *et al.*, 2013; Daumler *et al.*, 2016; García *et al.*, 2016). In addition, a higher educational level is linked to a higher possibility of recognizing fertility problems (Pedro *et al.*, 2018). It is well established that fertility declines with age, especially in women, for whom the chances of achieving pregnancy decline substantially at around the age of 35 (ASRM, 2012). Therefore, the large delays recorded by respondents will likely negatively impact chances of treatment success as a result of older age at treatment initiation. The significance of age-related fertility decline necessitates a greater public awareness of the benefits of childbearing at a younger age (ASRM, 2012).

The differences between countries in the time to receiving a medical infertility diagnosis may be a reflection of differences in healthcare systems and treatment funding offered. The longest time to receiving a medical infertility diagnosis was reported by respondents in the USA, which could result from healthcare system inefficiencies or financial concerns in a country where there is no federal mandate for infertility coverage. In states where coverage is mandated, higher treatment expenditures via treatment plans or employers are reported, indicating a greater usage of fertility services compared with states without a mandate (Boulet *et al.*, 2019). By contrast, the shortest average delays to receiving a medical infertility diagnosis were often reported in Australia and European countries such as Italy where infertility services are provided by the government (Calhaz-Jorge *et al.*, 2020; Morshed-Behbahani *et al.*, 2020). Therefore, further research should be conducted to explore the impact of different medical cultures and health

systems on the time taken to achieve pregnancy.

Motivational coherence within couples is important for seeking medical advice. Analysis of the drivers for respondents to seek treatment and then continue after failures to achieve parenthood with medical assistance showed that an equal desire within the couple to achieve pregnancy was important across patient and partner subgroups and most countries. This suggests that motivational coherence within couples is significant when making treatment decisions and in determining continuation on the infertility journey. Previous literature supports this idea as it has been shown that disagreements about fertility treatment within couples can impact on relationships and may influence their motivation to seek and continue with treatment (Brandes *et al.*, 2009; Klitzman, 2017).

Current literature suggests that the financial impact of fertility treatment represents a large barrier to female patients, and this study supports these findings. However, patients reported cost as a barrier more often than do the partners of infertile patients. This could suggest that patients are better informed about the fertility treatment journey and its implications than partners, and therefore partners may benefit from the HCP team taking a more couple-oriented approach to treatment. Further research is required into the perspectives of partners to explore this.

Communication remains an important aspect of patient-centred care. The transparency of the HCP team and the effectiveness of their communication with respondents were important drivers for respondents to seek treatment. Previous research has also established the importance of communication with the HCP team during treatment (Dancet *et al.*, 2012; Klitzman, 2018). Studies regarding patient-centred care for infertility have shown that the emotional support and information provided by the HCP, in addition to their competence and accessibility, are important factors for infertile patients (Dancet *et al.*, 2012). In Europe, provision of information regarding infertility is a top priority (Dancet *et al.*, 2012). These factors have been positively associated with patient well-being, suggesting that the HCP team can influence a patient's infertility

experience and quality of life (Dancet *et al.*, 2012; Gameiro *et al.*, 2013b; Harzif *et al.*, 2020).

The results of this study support these findings. Respondents who initiated treatment more frequently agreed with positive statements regarding the communication and helpfulness of the HCP team and their propensity to treat respondents as a couple rather than an individual, compared with those who did not seek treatment. These respondents also more frequently reported that their HCPs offered support services, mental health support and resources. This highlighted the significance of the HCP team in determining continuation of the treatment journey. HCP teams should therefore maintain a focus on good communication with infertile couples, provide them with information about their medical infertility diagnoses and consider whether they would benefit from additional emotional support. These results also highlight the importance of the inclusion of the partner, indicating the need for a more couple-centred approach to fertility treatment.

Despite sex differences, the cost of treatment remained the most significant overall barrier to consultation, initiating treatment and continuing with treatment. It is important to note that the 'cost of treatment' encompasses both the cost of fertility medications and the context of affordability of these treatments to patients and partners. Respondents from the USA cited cost as a barrier to both consultation and treatment more frequently than individuals from any other country, which is likely to be a reflection of the significantly higher costs and lack of nationwide publicly funded fertility treatments in the USA in contrast to most other developed countries (Morshed-Behbahani *et al.*, 2020; Mossialos and Wenzl, 2016). Results from Italy and France conversely reported consistently low concerns about the cost of treatment. However, the consistency with which respondents reported cost as a barrier throughout the treatment journey indicates that it is a significant issue, particularly in countries where fertility treatments are not publicly funded. Therefore, it is possible that the introduction of country-wide subsidized programmes similar to those in other countries could alleviate the concerns of a substantial proportion of infertile patients and their partners, and significantly



improve accessibility of treatment. Previous research has demonstrated that an investment in ART is both clinically and economically valuable, as the lifetime taxes paid by a child represent a return on investment (*Connolly et al., 2008; Matorras et al., 2015; Wei et al., 2021*). However, it should be noted that there were many respondents for whom cost of treatment was not an issue, and that 87.1% of those who received treatment reported some level of public or private coverage or funding.

Another mindset frequently reported as a barrier throughout the infertility journey was a determination to achieve pregnancy without assistance. This indicates the need for greater education for patients and partners regarding the lower chances of achieving pregnancy without assistance after years of trying and with a resultant older age (*ASRM, 2012*). The value of improved education has been demonstrated in a recent randomized controlled trial which found that this accelerated births among partnered individuals (*Maeda et al., 2018*). The physical effect of treatment was also a significant issue for respondents, corroborating previous findings in infertile patients (*Gameiro et al., 2012*). It is possible that improved patient support services would alleviate some of these negative perceptions and enable them to continue along their treatment journey. Variations between patient and partner responses indicate the need for further research into partner-reported barriers to fertility treatment.

This study corroborated findings already established in the literature regarding drivers and barriers to treatment and the importance of interaction with the HCP team, and generated new data on delays in the treatment journey. Additionally, this study explored the previously under-researched perspectives of partners of infertile patients, and male patients and partners. This allowed the comparison of male and female, and patient and partner, responses to highlight differences in the perceived barriers to fertility treatment. The study was designed to include a large sample size of 1944 respondents and had broad inclusion criteria.

A limitation of this study is that the anonymous questionnaire did not allow for response validation, for example with verification of infertility diagnoses

by medical professionals. Respondents were unable to ask clarifying questions. There was little constriction on the recall period, allowing for long periods of time to have passed since the respondents received a medical infertility diagnosis, which could reduce the validity of some responses. Furthermore, the recruitment of individual respondents into patient and partner subgroups meant that there were no sub-analyses of patient–partner pairs, and the cross-sectional nature of the study meant that causality could not be proven. Additionally, it is possible that some of the surveyed patients and partners were part of the same couple. Respondents who had received treatment received only ART, intrauterine insemination or donor gametes. Other fertility treatments are available and therefore all fertility treatment options were not captured in this study.

## CONCLUSIONS

This study highlights the significant delays in receiving a medical infertility diagnosis, indicating the need for better education surrounding treatment and the lower chances of success with longer delays and resultant older age. Motivational coherence within couples in the desire for a child was a key driver, and perceived supportive service offerings of the HCP team were important determinants of treatment journey continuation. These results are indicative of the need for support both within the couple and within the patient–provider relationship, and suggest that HCP teams should maintain an emphasis on open communication with patients and partners. Financial concerns were an important barrier to treatment, and country differences indicated the need for improved accessibility to treatments.

The analysis of subgroups showed that men and the partners of infertile patients have different experiences and perceptions of the fertility treatment journey from those of the female patient population already established in the literature. This indicates the requirement for further research to investigate the effects on these under-researched groups to improve care for both male and female patients and partners.

## ACKNOWLEDGEMENTS

The authors would like to thank the researchers at W2O Group who

developed the survey and collected the results for analysis and Adelphi Group for editorial assistance with the manuscript. This study was funded by Ferring Pharmaceuticals A/S.

## SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.rbmo.2021.09.002](https://doi.org/10.1016/j.rbmo.2021.09.002).

## REFERENCES

- ASRM. **Diagnostic evaluation of the infertile female: a committee opinion.** *Fertil. Steril.* 2012; 98: 302–307. doi:10.1016/j.fertnstert.2015.03.019
- Ballard, K., Lowton, K., Wright, J. **What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis.** *Fertil. Steril.* 2006; 86: 1296–1301. doi:10.1016/j.fertnstert.2006.04.054
- Boivin, J., Bunting, L., Collins, J.A., Nygren, K.G. **International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care.** *Hum. Reprod.* 2007; 22: 1506–1512. doi:10.1093/humrep/dem046
- Boivin, J., Bunting, L., Kalebic, N., Harrison, C. **What makes people ready to conceive? Findings from the International Fertility Decision-Making Study.** *Reprod. Biomed. Online* 2018; 6: 90–101. doi:10.1016/j.rbms.2018.10.012
- Boulet, S.L., Kawwass, J., Session, D., Jamieson, D.J., Kissin, D.M., Grosse SD., **US State-Level Infertility Insurance Mandates and Health Plan Expenditures on Infertility Treatments.** *Matern. Child Health J.* 2019; 23: 623–632. doi:10.1007/s10995-018-2675-y
- Brandes, M., van der Steen, JOM., Bokdam, S.B., Hamilton, CJCM., de Bruin, J.P., Nelen, WLD.M., Kremer, JAM. **When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population.** *Hum. Reprod.* 2009; 24: 3127–3135. doi:10.1093/humrep/dep340
- Bunting, L., Boivin, J. **Decision-making about seeking medical advice in an internet sample of women trying to get pregnant.** *Hum. Reprod.* 2007; 22: 1662–1668. doi:10.1093/humrep/dem057
- Calhaz-Jorge, C., De Geyter, C., Kupka, M.S., Wyns, C., Mocanu, E., Motrenko, T., Scaravelli, G., Smeenk, J., Vidakovic, S., Goossens, V. **Survey on ART and IUI: legislation, regulation, funding and registries in European countries: The European IVF-monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE).** *Hum. Reprod. Open* 2020; 1: hoz044. doi:10.1093/hropen/hoz044
- Chandra, A., Copen, C.E., Stephen, E.H. **Infertility service use in the United States: data from the National Survey of Family Growth, 1982–2010.** *National Health Statistics Reports* 2014; 73: 1–121
- Connolly, M.P., Pollard, M.S., Hoorens, S., Kaplan, B.R., Oskowitz, S.P., Silber, S.J. **Long-term economic benefits attributed to IVF-conceived children: a lifetime tax calculation.** *Am. J. Manag. Care* 2008; 9: 598–604
- Costa, M., Chiaffarino, F., De Stefano, C., De Stefano, C., Parazzini, F. **Timing, characteristics and determinants of infertility diagnostic work up before admission to eleven second-level assisted reproductive techniques (ART) centres in Italy.** *Eur. J. Obstet. Gynecol. Reprod. Biol.* 2013; 167: 53–58. doi:10.1016/j.ejogrb.2012.10.022
- Dancet, EAF, D'Hooghe, T.M., Sermeus, W., van Empel, I., Strohmer, H., Wyns, C., Santa-Cruz, D., Nardo, L.G., Kovatchki, D., Vanlangenakker, L., Garcia-Velasco, J., Mulugeta, B., Nelen, WLD.M., Kremer, JAM. **Patients from across Europe have similar views on patient-centred care: an international multilingual qualitative study in infertility care.** *Hum. Reprod.* 2012; 27: 1702–1711. doi:10.1093/humrep/des061
- Daumler, D., Chan, P., Lo, K.C., Takefman, J., Zelkowitz, P. **Men's knowledge of their own fertility: a population-based survey examining the awareness of factors that are associated with male infertility.** *Hum. Reprod.* 2016; 31: 2781–2790. doi:10.1093/humrep/dew265
- Dyer, S.J., Patel, M. **The economic impact of infertility on women in developing countries - a systematic review.** *Facts, Views Vis. Obgyn.* 2012; 4: 102–109
- Eisenberg, M.L., Smith, J.F., Millstein, S.G., Nachtigall, R.D., Adler, N.E., Pasch, L.A., Katz, P.P. **Predictors of not pursuing infertility treatment after an infertility diagnosis: examination of a prospective U.S. cohort.** *Fertil. Steril.* 2010; 94: 2369–2371. doi:10.1016/j.fertnstert.2010.03.068
- EphMRA., 2017. Code of Conduct. <https://www.ephmra.org/media/1785/ephmra-2017-code-of-conduct-october-2017.pdf>. Accessed 16/09/2021.
- Gameiro, S., Boivin, J., Peronace, L., Verhaak, C.M. **Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment.** *Hum. Reprod. Update* 2012; 18: 652–669. doi:10.1093/humupd/dms031
- Gameiro, S., Verhaak, C.M., Kremer, JAM., Boivin, J. **Why we should talk about compliance with assisted reproductive technologies (ART): a systematic review and meta-analysis of ART compliance rates.** *Hum. Reprod. Update* 2013; 19: 124–135. doi:10.1093/humupd/dms045
- Gameiro, S., Canavarro, M.C., Boivin, J. **Patient centred care in infertility health care: direct and indirect associations with wellbeing during treatment.** *Patient Educ. Couns.* 2013; 93: 646–654. doi:10.1016/j.pec.2013.08.015
- García, D., Vassena, R., Prat, A., Vernaev, V. **Increasing fertility knowledge and awareness by tailored education: a randomized controlled trial.** *Reprod. Biomed. Online* 2016; 32: 113–120. doi:10.1016/j.rbmo.2015.10.008
- Hadley, R., Hanley, T. **Involuntarily childless men and the desire for fatherhood.** *J. Reprod. Infant Psychol.* 2011; 29: 56–68. doi:10.1080/02646838.2010.544294
- Harrison, C., Gameiro, S., Boivin, J. **Patient willingness, preferences and decision making about planning for three complete cycles of IVF/ICSI treatment.** *Hum. Reprod.* 2021; 5: 1339–1352. doi:10.1093/humrep/deab040
- Harzif, A.K., Shafira, N., Mariana, A., Lovita, B.T., Mutia, H.D., Maidarti, M., Pratama, G., Wiweko, B. **Communication and Respect for Patient Value as Significant Factors in Patient-Centered Infertility Care: A Survey of Patients' Experiences in Two Infertility Centers.** *J. Hum. Reprod. Sci.* 2020; 13: 22–25. doi:10.4103/jhrs.JHRS\_62\_19
- Inhorn, M.C., Patrizio, P. **Infertility around the globe: new thinking on gender, reproductive technologies and global movements in the 21st century.** *Hum. Reprod. Update* 2015; 21: 411–426
- Jain, T., Hornstein, M.D. **Disparities in access to infertility services in a state with mandated insurance coverage.** *Fertil. Steril.* 2005; 84: 221–223. doi:10.1093/humupd/dmv016
- Klitzman, R. **How much is a child worth? Providers' and patients' views and responses concerning ethical and policy challenges in paying for ART.** *PLoS One* 2017; 12:e0171939. doi:10.1371/journal.pone.0171939
- Klitzman R., 2018. Impediments to communication and relationships between infertility care providers and patients. *BMC Women's Health.* 18. <https://doi.org/10.1186/s12905-018-0572-6>
- Kumar, N., Singh, A.K. **Trends of male factor infertility, an important cause of infertility: A review of literature.** *Journal of Hum. Reprod. Sci.* 2015; 8: 191–196. doi:10.4103/0974-1208.170370
- Langher, V., Fedele, F., Caputo, A., Marchini, F., Aragona, C. **Extreme Desire for Motherhood: Analysis of Narratives From Women Undergoing Assisted Reproductive Technology (ART).** *Eur. J. Psychol.* 2019; 15: 292–311. doi:10.5964/ejop.v15i2.1736
- Lemoine, M.E., Ravitsky, V. **Sleepwalking into infertility: the need for a public health approach toward advanced maternal age.** *Am. J. Bioeth.* 2015; 15: 37–48. doi:10.1080/15265161.2015.1088973
- Maeda, E., Boivin, J., Toyokawa, S., Murata, K., Saito, H. **Two-year follow-up of a randomized controlled trial: knowledge and reproductive outcome after online fertility education.** *Hum. Reprod.* 2018; 33: 2035–2042. doi:10.1093/humrep/dey293
- Matorras, R., Villoro, R., González-Domínguez, A., Pérez-Camarero, S., Hidalgo-Vega, A., Polanco, C. **Long-term fiscal implications of funding assisted reproduction: a generational accounting model for Spain.** *Reprod. Biomed. Online* 2015; 2: 113–122. doi:10.1016/j.rbms.2016.04.001
- Molina-García, L., Hidalgo-Ruiz, M., Cocera-Ruiz, E.M., Conde-Puertas, E., Delgado-Rodríguez, M., Martínez-Galiano, J.M. **The delay of motherhood: Reasons, determinants, time used to achieve pregnancy, and maternal anxiety level.** *PLoS One* 2019; 14:e0227063. doi:10.1371/journal.pone.0227063
- Morshed-Behbahani, B., Lamjani, M., Joulaei, H., Rashidi, B., Montazeri, A. **Infertility policy analysis: a comparative study of selected low-middle-and high-income countries.** *Glob. Health.* 2020; 16. doi:10.1186/s12992-020-00617-9
- Mossialos E., Wenzl M., 2016. 2015 International Profiles of Health Care Systems International Profiles of Health Care Systems. The Commonwealth Fund. [https://www.commonwealthfund.org/sites/default/files/documents/\\_\\_\\_media\\_files\\_publications\\_fund\\_report\\_2016\\_jan\\_1857\\_mossialos\\_intl\\_profiles\\_2015\\_v7.pdf](https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2016_jan_1857_mossialos_intl_profiles_2015_v7.pdf). Accessed: 22/04/2021.
- Pedro, J., Brandão, T., Schmidt, T., Costa, M.E., Martins, M.V. **What do people know about fertility? A systematic review on fertility awareness and its associated factors.** *Ups. J. Med. Sci.* 2018; 123: 71–81. doi:10.1080/03009734.2018.1480186
- Santos, T.M.V., Pereira, A.M.G., Lopes, R.G.C., Depes, D.B. **Lag time between onset of symptoms and diagnosis of endometriosis.** *Einstein (São Paulo)* 2012; 10: 39–43. doi:10.1590/S1679-45082012000100009
- Schmidt, L., Sobotka, T., Bentzen, J.G., Nyboe Andersen, A. **Demographic and medical consequences of the postponement of parenthood.** *Hum. Reprod. Update* 2012; 18: 29–43. doi:10.1093/humupd/dmr040
- Smith, J.F., Eisenberg, M.L., Glidden, D., Millstein, S.G., Cedars, M., Walsh, T.J., Showstack, J., Pasch, L.A., Adler, N., Katz, P.P. **Socioeconomic**

**disparities in the use and success of fertility treatments: analysis of data from a prospective cohort in the United States.** *Fertil. Steril.* 2011; 96: 95–101. doi:10.1016/j.fertnstert.2011.04.054

Sunkara, SK., Zheng, W., D'Hooghe, T., Longobardi, S., Boivin, J. **Time as an outcome measure in fertility-related clinical studies: long-awaited.** *Hum. Reprod.* 2020; 35: 1732–1739. doi:10.1093/humrep/deaa138

Wei, SQ., Bilodeau-Bertrand, M., Lo, E., Auger, N. **Effect of publicly funded assisted reproductive technology on maternal and infant outcomes:**

**a pre- and post-comparison study.** *Hum. Reprod.* 2021; 1: 219–228. doi:10.1093/humrep/deaa270

World Health Organization., 2004. Global prevalence of infertility, infecundity and childlessness. <https://www.who.int/reproductivehealth/topics/infertility/burden/en/>. Accessed 22/04/2021.

Wu, AK., Elliott, P., Katz, PP., Smith, JF. **Time costs of fertility care: the hidden hardship of building a family.** *Fertil. Steril.* 2013; 99: 2025–2030. doi:10.1016/j.fertnstert.2013.01.145

Zegers-Hochschild, F., Adamson, GD., de Mouzon, J., Ishihara, O., Mansour, R., Nygren, K., Sullivan, E., van der Poel, S. **The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary on ART Terminology, 2009.** *Hum. Reprod.* 2009; 24: 2683–2687. doi:10.1016/j.fertnstert.2009.09.009

Received 21 May 2021; received in revised form 9 August 2021; accepted 2 September 2021.