Predicting dropout in fertility care: a longitudinal study on patient-centredness

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STUDY QUESTION: Are clinic factors, including patients’ experiences with patient-centred care, associated with dropout in fertility care?

SUMMARY ANSWER: Clinic factors, including patients’ experiences with patient-centred care, are not related to dropout.

WHAT IS KNOWN ALREADY: In fertility care, a significant proportion of patients do not achieve pregnancy because they discontinue treatment prematurely. Many studies have tried to identify factors predicting dropout, showing incompatible results. However, these studies mainly focus on factors at the treatment and patient level, while clinic factors have received little attention.

STUDY DESIGN, SIZE, DURATION: This prospective, longitudinal study was nested within a large RCT, which aims to improve the level of patient-centredness of Dutch fertility care. Of the 1620 infertile women who were invited to participate, the baseline measurement of the study (T0) included 693 women who completed a questionnaire about their experiences with patient-centred fertility care. The follow-up of the patients was 1 year (T1).

PARTICIPANTS/MATERIALS, SETTING, METHODS: All included women suffered from infertility and were undergoing treatment in one of the 32 Dutch clinics involved in the trial. Levels of patient-centredness were determined using the Patient-Centredness Questionnaire-Infertility (PCQ-Infertility) at T0. Meanwhile, a professionals’ questionnaire was used to gather additional information on characteristics of the clinic (e.g., the number of patients per year or the presence of a fertility nurse). After 1 year, at T1 measurement, patients completed a questionnaire on their current status in fertility care, including their main reason for discontinuation if applicable.

MAIN RESULTS AND THE ROLE OF CHANCE: A total of 693 non-pregnant women completed the questionnaire set at T0 and 534 women (77.1%) provided consent for follow-up. At T1 measurement, 434 women (81.3%) completed the questionnaire and 153 of these women (35.2%) continued treatment while 76 women (17.5%) dropped out. Another 175 women (40.3%) had achieved pregnancy and 30 patients (7.9%) were advised to discontinue treatment for medical reasons. Neither levels of patient-centredness nor the additional clinic characteristics differed significantly between dropouts and compliers. However, patients who did not receive assisted reproduction treatment (ART; e.g., underwent intrauterine insemination, IUI) before they dropped out had significantly lower scores on the PCQ-Infertility subscale ‘Respect for patients’ values’ than patients who continued their treatment [odds ratio (OR) 0.57; 95% confidence interval (CI) 0.34–0.95]. Patients who received ART and, subsequently, dropped out had higher scores on the PCQ-Infertility subscale ‘Patient involvement’ than those receiving non-ART (OR 2.39; 95% CI 1.02–5.59).

LIMITATIONS, REASONS FOR CAUTION: We were not able to follow-up a significant proportion (ca. 19%) of the 1620 women who were invited for T0 measurement, which might have biased our results. We also excluded patients who were still in the diagnostic work-up stage and this might have influenced our results as it is known that patients dropout at this stage. As the PCQ-Infertility was validated in patients who were already undergoing treatment, we decided to focus on this patient group only.

WIDER IMPLICATIONS OF THE FINDINGS: The results of this study provide a better insight into those factors influencing dropout from the perspective of factors in the clinic itself. Although most clinic factors were not related to dropout, clinic factors might be of use when predicting...
Introduction

A successful fertility treatment is something every infertile couple is striving for. Unfortunately, a significant proportion of couples do not achieve pregnancy because of medical factors, but also because they discontinue treatment prematurely. The exact number of patients dropping out of fertility treatment varies across European studies and ranges from 17 to 70% (Olivius et al., 2004; Schröder et al., 2004; Rajkhowa et al., 2006; Verberg et al., 2008; Verhagen et al., 2008; Brandes et al., 2009; Gameiro et al., 2012). This wide range might be due to the conceptual issues around the definition of dropout and the methodological differences between studies (Boivin et al., 2012; Gameiro et al., 2012). However, it still indicates that treatment dropout concerns many infertile patients. It is worrisome that these couples decide to give up their dream of becoming parents, because of the physical or psychological burden they encounter during treatment. Therefore, prognostic factors for dropping out should be identified to develop interventions, which target specifically those burdensome aspects of treatment (Boivin et al., 2012; Gameiro et al., 2012).

When considering the reasons why patients discontinue treatment, one could think of reasons related to the patients themselves (e.g. their well-being) or the kind of treatments they receive (Boivin et al., 2012). Moreover, it might be expected that reasons related to the clinic itself, such as inadequate organization of care or poor communication skills of staff, influence patients’ decisions to discontinue fertility treatment prematurely. This is supported by the literature where, for example, inadequate information provision and coordination of care have been identified as reasons for dropout (Haagen et al., 2008). Also a lack of empathy by the staff, poor listening skills (Olivius et al., 2004) and negative interactions with staff (Rajkhowa et al., 2006) have been cited as reasons to discontinue treatment. Apparently, numerous clinic factors have been reported in connection with discontinuation (Boivin et al., 2012), but whether they could be used as a predictor of dropout has never been studied. It would be interesting to investigate this possible relationship through longitudinal research, as it shows us to what extent professionals could account for these factors in daily practice to prevent dropout.

To identify clinic factors as potential predictors of dropout, standard clinic characteristics could be studied (e.g. clinic size and presence of specialized fertility nurses). Furthermore, it would be valuable to ask infertile patients themselves about their experiences with fertility care in a clinic to identify relevant and predictive clinic factors for dropout. The recently developed and validated Patient-Centredness Questionnaire-Infertility (PCQ-Infertility) could be used for this goal, as it measures patient-centredness from the patients’ perspective in seven different and concrete dimensions (e.g. accessibility of care, continuity and transition and professionals’ competence; Van Empel et al., 2010a). Van Empel et al. (2011b) already showed that patients change clinics because they experience a lack of patient-centred care. Whether patients dropout during treatment because of a lower level of patient-centred fertility care is unknown.

Therefore, the main aim of this study was to identify clinic factors, including patients’ experiences with patient-centredness in their clinic, as potential predictors of dropout in fertility care, in a prospective manner. Furthermore, previous studies have shown that barriers to the uptake of treatment for dropout are common to all types of treatment, while others are type-specific (Brandes et al., 2009; Gameiro et al., 2012). Because van Empel et al. (2010b) found a significant association between treatment type [i.e. assisted reproduction treatment (ART) and non-ART] and patient-centred care, we wanted to study the relation between dropout and patient-centred care for these subgroups of patients as well.

Materials and Methods

Study design

This prospective longitudinal study was nested within a large RCT (Trial registration number: Clinicaltrials.gov NCT01481064), which aims to improve the level of patient centredness of Dutch fertility care (Huppelschoten et al., 2012). During the baseline measurement of this study (T0), patients completed a questionnaire on their experiences with patient-centred care. We used a questionnaire for professionals to gather additional clinic characteristics as potential predictors of dropout. One year later (T1), patients who gave consent for follow-up received a questionnaire on their current status in fertility care.

Setting

In the Netherlands, fertility care is provided by three different types of clinic based on the kind of treatment they offer. Almost all clinics carry out initial fertility assessment, ovulation induction (OI) and intrauterine insemination (IUI). A limited number of clinics can also start and monitor IVF and ICSI treatments, including the ovum retrieval. The laboratory phase of IVF and embryo transfers has to occur in one of the thirteen licensed fertility clinics. Almost all Dutch fertility clinics are funded by the National Health Service. Every Dutch citizen has a basic insurance coverage, which covers treatment and medication costs for OI, IUI and a maximum of three cycles of IVF/ICSI until couples achieve an ongoing pregnancy.

Study population

We performed this study in infertile patients receiving treatment in one of 32 participating Dutch clinics. All patients who participated underwent at least one cycle of medically assisted reproduction (MAR; e.g. OI, IUIs, IVF and ICSI). We only invited the women of the infertile couples to participate in our study as a previous study has shown that patients’ experiences with fertility care are comparable between infertile women and their partners (Huppelschoten et al., 2013). Patients who were already pregnant at T0
were excluded from follow-up, as our research question did not concern this patient group.

**Data collection**

**T0 measurement**

To include a representative patient group for T0 measurement, clinics were asked to extract from their medical records, the address files of all patients who underwent at least one cycle of MAR in their clinic in the previous 3 months (spring—summer 2011). From this list of patients, 25–75 patients per clinic were randomly selected depending on the clinic size.Selected women received a letter in which they were invited to complete an online questionnaire set, accessible by a personal code. Participation was voluntary and anonymous. Patients received a reminder card 2 weeks after the initial mailing. Another 3 weeks later, non-responders received a reminder with the additional option to complete a paper version of the questionnaire (Zuidgeest et al., 2011).

Per clinic, one gynaecologist (i.e. our contact) received an online questionnaire for professionals by e-mail. All 32 gynaecologists received a standard reminder after 2 weeks, and we sent the non-responders an additional reminder 3 weeks later.

**T1 measurement**

Only the patients who gave consent to follow-up were invited for the T1 measurement (summer 2012). The first steps of questionnaire distribution were performed in the same way as at T0 measurement. Subsequently, an additional reminder was sent to the final non-responders to achieve as high a response rate as possible. The questionnaire at T1 consisted of questions about patients’ current status in fertility care. In cases of dropout, we asked for patients’ most important reason for discontinuation. To do so, we provided them with a list of 10 different options for dropout, which was based on the literature (e.g. poor response, emotional reasons, ethical reasons or women’s age; Brandes et al., 2009; Gameiro et al., 2012). In case of no valid options, patients had the possibility to add their personal most important reason for discontinuation. Only those patients who discontinued their treatment prematurely were identified as dropouts. However, patients who ended treatment because they have had the maximum of three IVF/ICSI cycles or had no more treatment options were not considered as dropouts. The compliers group consisted of patients who were still under treatment in their own clinic, or patients who had no more treatment options in their own clinic and, therefore, went to another clinic. Patients who went to another clinic because they were unsatisfied with their clinic were excluded from analysis.

**Questionnaires at T0 measurement**

**Patients’ questionnaire**

The questionnaire set for patients consisted of several background questions for case-mix adjustment and the PCQ-Infertility questionnaire. The background questions were based on both general and fertility care related issues described in the literature as possibly being linked to dropout and/or patient-centred care (van Empel et al., 2010b, 2011a; Mourad et al., 2010; Nefs et al., 2011; Cho et al., 2013), including issues related to the quality of life (FertiQol questionnaire; Boivin et al., 2011) and risk factors for emotional maladjustment during treatment (SCREENIVF questionnaire; Verhaak et al., 2010).

The PCQ-Infertility is a validated instrument measuring patient-centeredness of fertility care by asking patients about their experiences with care. This questionnaire is composed of 46 questions and contains 7 subscales, namely: accessibility (two items, Cronbach’s α = 0.64, e.g. ‘Was it a problem for you to contact staff if you had any questions?’); information (11 items, Cronbach’s α = 0.73, e.g. ‘Did you receive an overview of your treatment plan with a time schedule?’); communication (seven items, Cronbach’s α = 0.78, e.g. ‘How often did your physician take you seriously?’); respect for patients’ values (seven items, Cronbach’s α = 0.85, e.g. ‘How often did your physician show an interest in your personal situation?’); continuity and transition (seven items, Cronbach’s α = 0.66, e.g. ‘How often did you have an appointment with the same physician?’); patient involvement (three items, Cronbach’s α = 0.75, e.g. ‘Was decision-making shared with you, if preferred?’) and competence (six items, Cronbach’s α = 0.72, e.g. ‘How often was your physician well-prepared for an appointment?’). A higher score on the total PCQ scale or one of the subscales (range 0–3) indicates a higher level of experienced patient-centeredness (van Empel et al., 2010a).

**Professionals’ questionnaire**

We used a questionnaire for professionals to gather the remaining clinic characteristics as potential predictors of dropout. The representative gynaecologists of all 32 participating clinics received a short online questionnaire with eight questions about their clinic. The selection of the clinic characteristics was based on the literature as possibly being related to patient-centred care (van Empel et al., 2010b, 2011a; Mourad et al., 2010), and included the number of gynaecologists, the number of new fertility patients per year, presence of a separate waiting room for infertile patients (yes/no), a separate room for semen production (yes/no), specialized fertility nurse(s) (yes/no), having a psychologist as part of the fertility team (yes/no), structured (e.g. weekly) meetings to discuss all (new) patients within the team (yes/no) and execution of structured (e.g. yearly) quality measurements before the start of this study (yes/no).

**Ethical approval**

The institutional ethics committee of Radboud University Nijmegen Medical Centre provided ethical approval for this research to proceed (CMO nr 2011/034). A written informed consent had been obtained at T0 from all participants.

**Data analysis**

We first performed a power analysis using the model of Tosteson (Tosteson et al., 2003). We considered an odds ratio (OR) of 1.5–2.0 for 1 SD increase in exposure as clinically relevant, resulting in a minimum required number of 115 to 317 patients (α = 0.05, β = 0.8).

We categorized all patients into five groups depending on their current status in fertility care and compared all background characteristics between these groups. The five groups included (i) patients who had achieved pregnancy between T0 and T1; (ii) patients who were still under treatment (i.e. compliers); (iii) patients who dropped out of treatment; (iv) patients who ended treatment for medical reasons (e.g. having the maximum of three IVF cycles, or poor prognosis) and (v) patients who were lost to follow-up. We used one-way analysis of variance and chi-square tests to compare these groups on continuous and categorical patient characteristics, respectively.

For further analyses, we used the data of Groups 2 (i.e. compliers) and 3 (i.e. dropouts), as our research question concerned these patients only. Patient characteristics that showed significant differences between these two groups were taken up as case-mix adjusters in the final analysis. Subsequently, all clinic characteristics were included in multiple binary logistic regression analyses to evaluate them as a potential predictor of dropout. Compliers and dropouts acted as the dependent variable.

For our additional analysis, we divided our patient group into patients undergoing ART and patients undergoing non-ART at T0. Then, we determined to what extent the treatment type and PCQ-Infertility total scores were related to each other, using linear regression analyses. In case of a
significant correlation, we performed our previous analyses on these two groups separately.
Significance for all analyses was set at $P < 0.05$. Analyses were performed using the Statistical Package for the Social Sciences (version 18.0 for Windows®, SPSS Inc., Chicago, IL, USA).

**Results**

At T0 measurement, 1620 women were invited to participate, of which 946 completed the questionnaire (response rate 58.4%). After excluding 253 pregnant women, 693 women were eligible for participation in the follow-up study. Of this group, 534 women (77.1%) provided consent for the follow-up. At T1 measurement, 434 women completed the questionnaire (response rate 81.3%). Of these women, 175 (40.3%) had achieved pregnancy and 153 women (35.2%) continued treatment for the follow-up. At T1 measurement, 434 women completed the questionnaire (response rate 81.3%). Of these women, 175 (40.3%) had achieved pregnancy and 153 women (35.2%) continued treatment since T1 measurement. Of these women, 12 (7.8%) changed clinics because they were unsatisfied with the care they received in their clinic and were, therefore, excluded, leaving 141 patients in the compliers group. Further, a total of 76 women (17.5%) dropped out treatment and were, therefore, excluded, leaving 141 patients in the compliers group. Additional analyses on the subgroup of patients who went to another clinic because they were unsatisfied (OR 2.39; 95% CI 1.02–5.59).

We found no significant differences within both subgroups for the additional clinic characteristics.

**Discussion**

This study shows that patients’ experiences with patient-centred fertility care are not related to dropout, as the PCQ-Infertility scores did not differ between patients who continue and patients who discontinue their fertility treatment. Also the additional clinic characteristics were not related to dropout. However, when focusing on subgroups of patients, the PCQ-Infertility subscale ‘Respect for patients’ values’ negatively predicted dropout in patients receiving non-ART. Moreover, the subscale ‘Patient involvement’ was a positive predictor of dropout in patients undergoing ART treatments. These are important findings as clinic factors have rarely been studied as potential predictors of dropout. Therefore, the results of this study provide more insights into fertility clinics’ characteristics that do and do not predict dropout and the direction (i.e. positive or negative) in which this prediction might be.

It is remarkable that the level of patient-centredness that patients assign to their clinic was not related to dropout, since both qualitative and quantitative studies showed that infertile patients consider their clinic’s level of patient-centredness very important (van Empel et al., 2010b, 2011b; Dancet et al., 2011). A study of van Empel et al. (2011b) also demonstrated that patients were willing to trade off up to a third of their pregnancy rate for more patient-centred care. Moreover, a lack of patient-centredness was found as the most common reason for patients to change clinics (Malin et al., 2001; van Empel et al., 2011b). These findings notwithstanding, we can now conclude that, in our study setting, patients’ experiences with patient-centred care seem to be no optimal predictor of dropout. Still, it might be too restrictive to state that clinic factor could never be used as a predictor of dropout. Our study was performed within one European country, while it is known that the quality of care varies according to cultural and social settings (Groenewegen et al., 2005; Valentine et al., 2008). Extending our study to a more international setting might, therefore, influence the results. Moreover, dropout in relation to patient-centred care could be more relevant for specific treatment types (Gameiro et al., 2012), as we have shown in our study. First, patients who received non-ART had more chance of dropping out when they scored lower on the ‘respect for patients’ values’ subscale (i.e. a negative predictor). It is already known from the literature that non-ART patients are generally more dissatisfied with their care than patients receiving ART (van Empel et al., 2010a, 2011a; Mourad et al., 2010). This can be better understood, knowing that non-ART procedures are generally performed in less specialized fertility clinics, by more general gynaecologists compared with the more specialized gynaecologists and nurses in fertility centres. Our study showed that especially patients undergoing non-ART are sensitive to the respect they receive from the professional team. As a result, paying less attention to patients’ values led to more dropouts, which can be considered a negative effect in fertility care. Therefore, professionals treating non-ART patients should give these patients the personal attention they need and respect them in their values and needs.

The second possible predictor of dropout in our additional analyses was ‘Patient involvement’. Patients receiving ART were more likely to dropout when the level of patient involvement was higher (i.e. a positive predictor). Patients do not always know that they also have the option to
withdraw from treatment. Achieving awareness of this and involving patients in the decision process could make this clear to them (Davison, 2006). Apparently, patients’ decision to discontinue treatment is taken more easily when they are well informed and involved in all treatment phases, as we have shown in our study. Other studies in fertility care illustrate this as well. For example, Van Peperstraten et al. (2010) found that empowering infertile patients by giving them a decision aid made them choose to replace fewer embryos in IVF. Also, studies from other health care areas have shown the relation between patient empowerment and a reduction in care consuming (Stacey et al., 2011; Arterburn et al., 2012). From this point of view, dropping out or discontinuing treatment might be considered a positive choice in fertility care as it is well informed and without decisional conflict.

This line of thought could shed light on the complex issue of dropout. Dropping out of treatment could be a positive, well-informed choice. This decisional process seems to be supported by involving patients in their care and by respecting their values regarding treatment options. On the other hand, a negative choice to dropout could be explained by an inability to continue because of emotional or other personal reasons. This is supported by studies indicating stress or emotional strain as reasons for dropout. In previous research, dropout is mainly considered as a negative decision as patients were unsatisfied with the organization of care or mentioned poor communicating skills of the staff as their reason for discontinuation (Olivius et al., 2004; Haagen et al., 2008). The results of our study might indicate that patients’ decision to dropout of fertility care is more heterogeneous, as their decision was related to negative evaluations of patient-centred care (i.e. less respect of patients’ values), but also to positive evaluations (i.e. more patient involvement). We might, therefore, speak about dropouts as following a positive or after a negative choice (Duggan et al., 2006). To underline or reject this hypothesis, more research is obviously needed, for example, regarding the process underlying the decisions that infertile patients make. The results of our study could be helpful in the initiation of future research about this topic.

This study has several strengths. First, we included more than 500 infertile women from all areas across the Netherlands, ensuring representativeness of the Dutch infertile population. Second, we included patients in different treatment phases, while previous studies mainly focused on patients undergoing IVF and/or ICSI treatments. By including such a varied group of patients, we were able to evaluate predictors of dropout in almost the entire setting of fertility care. Moreover, we performed additional analyses, enabling us to draw conclusions on the different treatment phases as well. Third, we explored all different elements of ‘clinic factors’ by including both ‘standard clinic characteristics’ (e.g. clinic size) and clinic factors evaluated by the patients themselves. By including the PCQ-Infertility questionnaire, we were able to evaluate clinics from the perspective of the patients. Finally, we compared various patient characteristics between the dropouts and compliers, including patients’ quality of life, and corrected them if necessary. We also added the non-responders to this comparison, showing that their background characteristics did not differ significantly from the patients we included in the analysis.

Some limitations of this study should also be discussed. First, we were not able to follow-up all 534 patients who provided consent for this study at T0, which might have biased our results. However, due to the effort of sending additional reminders, we managed to reach a response rate of >80% at the T1 measurement. It should, however, be noticed that the response rate of T0 was 58.4% and, subsequently, we lost 22.9%
### Table I  Background characteristics of the cohort ($n = 534$) in a longitudinal study to identify factors, which predict dropout in fertility care.

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>Pregnant ($n = 175$)</th>
<th>Compliers ($n = 141$)</th>
<th>Dropout ($n = 76$)</th>
<th>Medical reasons ($n = 30$)</th>
<th>Lost to follow-up ($n = 100$)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age (Years)</td>
<td>32 (21–42)</td>
<td>32 (23–42)</td>
<td>34 (24–44)</td>
<td>37 (26–42)</td>
<td>32.0 (22–44)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Ethnic background (%)</td>
<td>91.4/2.9/5.7</td>
<td>87.2/5.0/7.8</td>
<td>90.8/5.3/3.9</td>
<td>93.3/3.3/3.3</td>
<td>88.3/1.9/9.7</td>
<td>0.57</td>
</tr>
<tr>
<td>Level of education (%)</td>
<td>53.4/40.6</td>
<td>45.5/48.6</td>
<td>48.7/51.3</td>
<td>73.3/26.7</td>
<td>53.4/46.6</td>
<td>0.04</td>
</tr>
<tr>
<td>Median duration of infertility (Months)</td>
<td>29 (3–133)</td>
<td>34 (1–103)</td>
<td>34 (4–142)</td>
<td>40 (2–104)</td>
<td>35 (5–121)</td>
<td>0.19</td>
</tr>
<tr>
<td>Median duration of fertility care experience (Months)</td>
<td>14 (1–109)</td>
<td>17 (1–86)</td>
<td>21 (1–127)</td>
<td>30 (4–89)</td>
<td>19.0 (1–118)</td>
<td>0.02</td>
</tr>
<tr>
<td>Diagnosis (%)</td>
<td>20.7/34.1/13.4/31.7</td>
<td>20.5/29.5/8.2/41.8</td>
<td>17.9/38.4/13.4/40.3</td>
<td>37.0/22.2/11.1/29.6</td>
<td>20.2/31.6/11.0/36.8</td>
<td>0.56</td>
</tr>
<tr>
<td>Treatment type (%)</td>
<td>42.9/57.1</td>
<td>45.6/54.4</td>
<td>45.3/54.7</td>
<td>93.3/6.7</td>
<td>46.0/54.0</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Professional emotional support (%)</td>
<td>10.4</td>
<td>12.1</td>
<td>11.8</td>
<td>10.3</td>
<td>14.0</td>
<td>0.90</td>
</tr>
<tr>
<td>Lifetime events (%)</td>
<td>11.5</td>
<td>14.9</td>
<td>7.9</td>
<td>10.0</td>
<td>4.9</td>
<td>0.08</td>
</tr>
<tr>
<td>Median FertiQoL score (0–100, range)</td>
<td>69.8 (32.3–95.2)</td>
<td>70.8 (27.1–92.7)</td>
<td>70.8 (37.5–90.6)</td>
<td>72.9 (35.4–91.7)</td>
<td>66.7 (31.3–96.8)</td>
<td>0.44</td>
</tr>
<tr>
<td>SCREENIVF (%)</td>
<td>63.2</td>
<td>65.9</td>
<td>60.6</td>
<td>69.2</td>
<td>65.6</td>
<td>0.81</td>
</tr>
</tbody>
</table>

1One-way analysis of variance and Chi-square tests were used for continuous and categorical variables, respectively. For ethnic background, the ‘Statistics Netherlands’ classification was used. This Dutch governmental institution classifies ethnicity according to the citizens’ country of birth and to that of their parents. Immigrants include both those who are foreign-born (first generation) and those who have at least one foreign-born parent (second generation). Categories were: (i) Dutch, (ii) Western (Europe, USA, Canada, Australia, New Zealand, Japan and Israel) and (iii) non-Western (immigrants from remaining countries, including Morocco, Surinam and Turkey).

2Low = primary or lower vocational education; middle = secondary or intermediate vocational education; high = higher professional education or university.

3Irregular ovulation, polycystic ovary syndrome, tubal factor, endometriosis and mucus hostility.

4Both male and female infertility diagnosis found.

5ART encompassed IVF, IVM, ICSI, cryopreservation and testicular sperm extraction.

6Non-ART included OI and IUI with or without controlled ovarian stimulation.

7Receiving professional emotional support by a psychologist in the last 3 months.

8Recently experienced (last 3 months) life-time event, interfering with patients’ daily life, e.g. financial, work or relational problems.

9The internationally developed and validated FertiQoL questionnaire measures infertile patients’ level of quality of life on a scale from 0 to 100. Higher scores means higher levels of quality of life.

10The SCREENIVF questionnaire consists of 34 questions covering five emotional maladjustment scales: anxiety, depression, helplessness, lack of acceptance regarding fertility problems and perceived social support. Scores on the SCREENIVF questionnaire reflect the percentage of patients having at least one of the five risk factors for increased emotional problems during fertility treatment.

11Both the ‘dropout’ and the ‘medical reasons’ groups differ significantly ($P < 0.05$) from the other groups.

12The ‘medical reasons’ group differs significantly ($P < 0.05$) from the other groups.

13Both the ‘pregnant’ and the ‘medical reasons’ groups differ significantly ($P < 0.05$) from the other groups.
of patients between T0 and T1, because they were not willing to participate in our prospective study. Bias of our results is, therefore, more likely and should be taken into account when interpreting our results. Second, we only included patients who already started treatment for their fertility problem and, consequently, left out those patients who dropped out during or even before diagnostic fertility work-up. Brandes et al. (2009) showed that already at this stage, patients drop out. However, the PCQ-Infertility was not validated for this group of patients, as they have not visited their clinic often enough to evaluate it appropriately. Consequently, we decided not to include these patients in our study. Third, we used a definition for dropout that might be somewhat different from the definition used in several other studies. Generally, dropout is defined as every premature discontinuation of treatment in that particular clinic. As we included patients from different clinics across the Netherlands and from all different treatment types, our study setting was somewhat different. Consequently, patients also ended treatment in their clinic, because they needed a treatment in another clinic or simply had no more treatment options. Because of this specific situation, we decided to exclude these patients from the dropout group. Following the literature, these patients can be considered as ‘active censored’ or ‘physician-recommended dropouts’. Consequently, we included patients who were ‘passive censored’ or ‘patient-initiated dropouts’ (Smeenk et al., 2004; van Dongen et al., 2010). We also excluded patients who went to another clinic because they were unsatisfied with their

Table II The relation between the level of patient-centredness and dropout.

<table>
<thead>
<tr>
<th></th>
<th>Compliers (n = 141)</th>
<th>Dropout (n = 76)</th>
<th>Compliers versus dropouts OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (range)</td>
<td>Median (range)</td>
<td></td>
</tr>
<tr>
<td>Total PCQ-Infertility (0–3)</td>
<td>2.24 (1.04–2.93)</td>
<td>2.18 (0.67–2.95)</td>
<td>0.73 (0.37–1.46)</td>
</tr>
<tr>
<td>Accessibility of care</td>
<td>2.50 (0.00–3.00)</td>
<td>2.50 (0.50–3.00)</td>
<td>1.07 (0.71–1.61)</td>
</tr>
<tr>
<td>Information provision</td>
<td>2.09 (0.60–3.00)</td>
<td>2.00 (0.00–3.00)</td>
<td>0.79 (0.49–1.30)</td>
</tr>
<tr>
<td>Communication</td>
<td>2.57 (0.57–3.00)</td>
<td>2.57 (0.14–3.00)</td>
<td>0.82 (0.47–1.43)</td>
</tr>
<tr>
<td>Respect for patients’ values</td>
<td>2.00 (0.14–3.00)</td>
<td>1.80 (0.00–3.00)</td>
<td>0.72 (0.49–1.05)</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>1.86 (0.67–3.00)</td>
<td>1.79 (0.43–3.00)</td>
<td>0.87 (0.52–1.46)</td>
</tr>
<tr>
<td>Patient involvement</td>
<td>2.33 (0.00–3.00)</td>
<td>2.67 (0.33–3.00)</td>
<td>1.24 (0.78–1.97)</td>
</tr>
<tr>
<td>Staff competence</td>
<td>2.50 (1.17–3.00)</td>
<td>2.50 (0.67–3.00)</td>
<td>0.80 (0.40–1.62)</td>
</tr>
</tbody>
</table>

Data presented as OR and 95% CI. Binomial logistic regression analysis was used to compare patients under treatment with patients who dropped out treatment. The results are adjusted for age.

Table III The relation between additional clinic characteristics and dropouts.

<table>
<thead>
<tr>
<th>Clinic characteristics</th>
<th>Compliers (n = 141)</th>
<th>Dropout (n = 76)</th>
<th>Compliers versus dropouts OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients per clinic</td>
<td>444 (110–2600)</td>
<td>500 (110–2600)</td>
<td>1.00 (1.00–1.01)</td>
</tr>
<tr>
<td>Separate waiting room for infertile patients</td>
<td>55 (39.0)</td>
<td>23 (30.3)</td>
<td>0.65 (0.35–1.19)</td>
</tr>
<tr>
<td>Specialized fertility nurses</td>
<td>96 (68.1)</td>
<td>57 (75.0)</td>
<td>1.57 (0.82–3.02)</td>
</tr>
<tr>
<td>Regularly measuring clinic’s quality levels</td>
<td>77 (54.6)</td>
<td>39 (51.3)</td>
<td>0.88 (0.50–1.56)</td>
</tr>
<tr>
<td>Structured meetings to discuss all patients</td>
<td>116 (82.3)</td>
<td>67 (88.2)</td>
<td>1.80 (0.78–4.18)</td>
</tr>
<tr>
<td>Number of gynaecologists</td>
<td>3 (1–7)</td>
<td>2 (1–7)</td>
<td>0.81 (0.67–1.00)</td>
</tr>
<tr>
<td>Separate semen production room</td>
<td>89 (63.1)</td>
<td>47 (61.8)</td>
<td>1.11 (0.61–2.02)</td>
</tr>
<tr>
<td>Presence of clinic psychologist(s)</td>
<td>116 (82.773)</td>
<td>62 (81.8)</td>
<td>0.96 (0.46–2.03)</td>
</tr>
</tbody>
</table>

Data presented as OR’s and 95% CI. Binomial logistic regression analysis was used to compare patients under treatment with patients who dropped out treatment. The results are adjusted for age.
current clinic, as they did not fit our definitions of ‘dropouts’ or ‘compliers’. However, we considered this an interesting subgroup of patient and performed additional analyses on this group. We found no relation to dropout, but this could very well be due to the small sample size (n = 12).

The results of our study led to some recommendations for daily practice and future research.

The fact that we did not find any association between clinic factors and dropouts in our entire patient group could imply that this association does not exist at all. If this is true, dropouts might be more related to patient-centredness to their experience with their own clinic, which could explain the lack of significant relationships. In addition, dropout might be explained by a complex interplay of clinical, personal and treatment-related factors (Boivin et al., 2012). It is possible that clinical factors play a role in patients who experience a lot of distress. This means that the results of this study do not justify the exclusion of clinical factors as possible contributors to dropout. More in-depth analyses are warranted to control for clinical differences, which will require large samples. Obviously, predicting dropout in fertility care is complicated given the number of studies on this subject and their conflicting outcomes (De Vries et al., 1999; Sharma et al., 2002; Pellick et al., 2007; Verbiest et al., 2008; Pearson et al., 2009; Domar et al., 2010; Custers et al., 2013). We have made a first initiative to show the relation between clinic factors and dropouts in a prospective setting. Future research should concentrate on more different patient, treatment and clinic factors and their possible interactions in order to identify appropriate predictors of dropout in fertility care.

In conclusion, patients’ experiences with patient-centred fertility care are not related to dropout. However, within two subgroups of patients (i.e. receiving non-ART and ART), we have collected some clues that clinic factors could be used as a predictor of dropout in specific patient groups. In future research, it would be interesting to find more predictors of dropout at the patient, treatment and clinic levels and explore their possible interactions. Only then, will we gain an optimal insight into those factors influencing dropout, making it possible to account for them in daily clinical practice.

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**Authors’ roles**

A.G.H., C.M.V., J.A.M.K. and W.L.D.M.N. designed the study. A.G.H. developed and managed the main database, interpreted the data and drafted the paper. A.J.C.M. interpreted the data and drafted the paper. I.C.P.P. developed and managed the main database. C.M.V. and C.J.C.M.H. revised critically for important intellectual content. J.A.M.K. contributed to the interpretation of data and revised critically for important intellectual content. W.L.D.M.N. interpreted the data and drafted the paper. All authors gave final approval of the version to be published.

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**Conflict of interest**

None declared.

**References**


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