


Lost and lonely: a qualitative study of women's experiences of no embryo transfer owing to non-fertilization or poor embryo quality

Herborg Holter ^{1,*}, Christina Bergh², and Ann-Louise Gejervall²

¹Department of Obstetrics and Gynaecology, Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University, Reproductive Medicine, Sahlgrenska University Hospital, Gothenburg SE-41345, Sweden ²Department of Obstetrics and Gynaecology, Institute of Clinical Sciences, Sahlgrenska Academy, Gothenburg University, Reproductive Medicine, Sahlgrenska University Hospital, Gothenburg SE-41345, Sweden

*Correspondence address. Department of Obstetrics and Gynaecology, Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University, Reproductive Medicine, Sahlgrenska University Hospital, Gothenburg SE-41345, Sweden.
E-mail: herborg.holter@gu.se  <https://orcid.org/0000-0001-7341-5619>

Submitted on August 18, 2020; resubmitted on November 18, 2020; editorial decision on November 23, 2020

STUDY QUESTION: What are the experiences of women undergoing IVF who could not receive an embryo transfer because of failed fertilization or poor embryo development?

SUMMARY ANSWER: No embryo transfer because of failed embryo development is associated with considerable emotional suffering and the need for an early appointment with a physician to obtain information on what went wrong and new alternatives.

WHAT IS KNOWN ALREADY: The psychological and emotional impact of IVF treatments as experienced by IVF patients is well known, particularly following the failure to achieve pregnancy.

STUDY DESIGN, SIZE, DURATION: A qualitative study running from January 2018 to April 2019 was carried out at one public and one private IVF clinic. The invitation to participate was sent to women within 1 month after the cycle failed.

PARTICIPANTS/MATERIALS, SETTING, METHODS: The women undergoing IVF were diverse in terms of cause of infertility, age, number of previous cycles, country of birth and educational level. Nineteen of the 41 invited women who had experienced no embryo transfer because of non-fertilization or poor embryo development took part in a semi-structured interview. Data were analysed by thematic content analysis.

MAIN RESULTS AND THE ROLE OF CHANCE: The master theme was identified as: 'Lost and lonely' organized in two main themes 'Experience of the event' and 'Perception of needs from healthcare providers'. Considerable emotional suffering was recognized after no embryo transfer. The need for support was expressed as to be offered an early appointment with a physician for information about what went wrong, looking at new alternatives and, for many women, providing information about counselling.

LIMITATIONS, REASONS FOR CAUTION: Only women participated, not partners. Of the women invited, 46% participated. Several declined to participate because of high levels of emotional stress.

WIDER IMPLICATIONS OF THE FINDINGS: Patients undergoing IVF and not achieving embryo transfer due to poor embryo development are a vulnerable group. They need early feedback concerning reasons for failure and future alternatives. They also require psychological support. This ought to be offered by IVF clinics.

STUDY FUNDING/COMPETING INTEREST(S): The study was financed by grants from the Swedish state under the agreement between the Swedish government and the county councils, the ALF-agreement (ALFGBG-70940). It was also financed by the Local Research and Development Board for Gothenburg and Södra Bohuslän (VGFOUGSB-866771) and by Hjalmar Svensson's research foundation (HJSV-2017012). None of the authors declares any conflicts of interest.

LARGE SCALE DATA: N/A.

Key words: IVF treatments / no embryo transfer / quality of care / psychological support / patient-centred care / emotional stress / non-fertilization / poor embryo quality

WHAT DOES THIS MEAN FOR PATIENTS?

One way of helping couples to conceive is to offer them IVF treatment, where the woman's egg is removed, fertilized outside her body and the resulting embryo is transferred to her uterus. The emotional strain of going through IVF treatment is well known, particularly if the treatment does not lead to the birth of a longed-for baby. An early failure occurs in about 1 in 10 IVF cycles, when an embryo is not transferred to the woman either because fertilization failed, or the embryo did not develop normally. Our study interviewed 19 women who had been through this distressing experience and asked them to describe it. We also asked them about the sort of support they would have liked the IVF clinic to provide at this difficult time. This included being offered an early appointment with a physician to find out what had gone wrong, information about new alternative treatments and information about counselling.

Introduction

The psychological and emotional impact of IVF treatments on patients is well known (Boivin et al., 1998; Schmidt, 2006; Cipoletta and Faccio, 2013; Rockliff et al., 2014). The experience of failure to achieve a pregnancy or 'no take-home baby' is documented as a risk factor for emotional distress (Verhaak et al., 2005, 2007; Volgsten et al., 2010; Karaca et al., 2016).

Previous studies evaluating why patients discontinue IVF treatment have found significant reasons to be emotional distress and psychological pressure (Olivius et al., 2004; Smeenk et al., 2004; Brandes et al., 2009; Gameiro et al., 2012; Domar et al., 2018).

ESHRE has published recommendations for psychosocial care in relation to infertility, based on the best available evidence in the literature (Gameiro et al., 2015). IVF treatments are reported to affect patients in several ways. Times specifically associated with a high degree of stress and anxiety are the periods between oocyte retrieval and embryo transfer, and waiting for pregnancy tests. High levels of emotional distress and depressive symptoms are common when pregnancy is not achieved. Evidence-based information for fertility staff on how to understand and meet patients' needs for psychosocial care in these demanding stages of treatment are described in detail, as are the patients' overall needs before, during and after treatment (Gameiro et al., 2015).

However, there is a lack of knowledge about patients' experiences of treatment failure when, owing to no fertilization or poor embryo quality, no embryo transfer takes place.

The patient questionnaire QPP-IVF (Quality from Patient's Perspective), a validated instrument used by all IVF clinics in Sweden since 2013, measures the patient's experience of quality of care (Holter et al., 2014a). According to national surveys using the QPP-IVF instrument, ~10% of all IVF cycles where oocyte retrieval is performed do not result in embryo transfer because of non-fertilization, or poor embryo quality. The results from the national surveys reveal that the vast majority of patients reported deficiencies in information and support from IVF clinics in regard to this failure.

The aim of the present study is to investigate women's experiences of not receiving embryo transfer owing to non-fertilization or poor embryo quality, as well as their need for support from healthcare providers at the relevant IVF clinics.

Materials and methods

Settings

The study took place at two Swedish IVF clinics, one public and one private, between January 2018 and April 2019.

Study participants and procedure

Women to whom an embryo was not transferred owing to non-fertilization or poor embryo quality were invited to participate in the study. The invitation was sent within 1 month after the cycle failed. The inclusion criterion was the ability to communicate in Swedish. In total, 41 women received a letter with an invitation to participate in an interview about their experience. Two weeks later, the women were contacted by telephone by one of the two researchers (H.H. or A.-L.G.) and if they were willing to participate, an interview was arranged. An interval of about 6 weeks from the failed embryo transfer was left to give the women some weeks to recover emotionally from a failed cycle. Of the 41 invited, 19 women (46.3%) consented to participate in the study. For details, see flow chart (Fig. 1). If needed, all

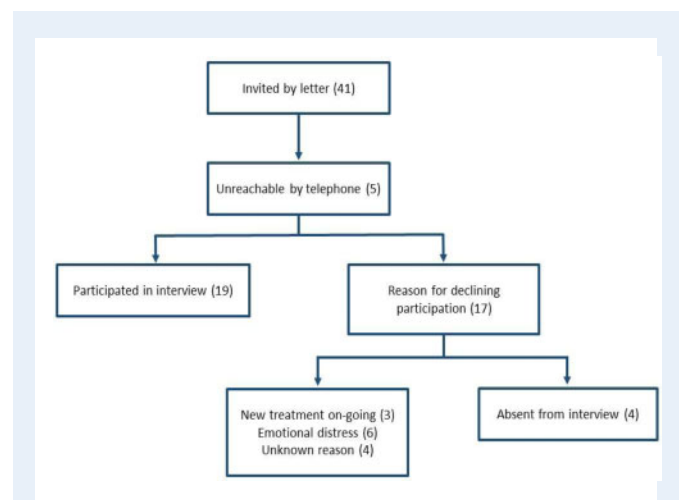


Figure 1. Flow chart of recruitment of participants in a study of women's experiences of no embryo transfer during IVF treatment.

women in the study were offered counselling with a psychologist after the interview.

The participants undertaking IVF treatments represented a diverse range of women in terms of cause of infertility, age, number of previous cycles, country of birth and educational level. Characteristics of participants and non-participants are given in Table I. Of the participating women, at the time 15 were undergoing treatments at the public clinic and four at the private clinic. None of the women had a diagnosis of psychiatric disorders, but two women had suffered from mild depression and anxiety.

The women were interviewed by one of the two researchers (H.H. or A.-L.G.), in a counselling room at one of the two clinics, or in a room at the University of Gothenburg, at a time chosen by the women. The women completed consent forms before the interview started. Women were informed that participation was voluntary and could be cancelled at any time without any impact on their further treatment. The semi-structured interview was audio-recorded and lasted ~1 h (between 50 and 120 min). Recordings were transcribed verbatim by a skilled transcriber and identifying details were removed or amended. The interview followed a semi-structured guide with two main themes: experiences of discontinued IVF treatment owing to non-fertilization or poor embryo quality; and the experience and need for support from healthcare providers after this event. The interview started with an open question: 'You are participating in this study because you did not receive embryo transfer. Can you start by describing

this experience?' Then the respondents narrated freely and further questions from the interviewer were seldom needed. Examples of questions occasionally asked were: 'Did you receive information about the possibility of no embryo transfer before starting treatment?', 'What did you think when you received the information that there was no embryo to be transferred?', 'How do you experience the support from the health care providers after this event?' and 'What kind of other support do you think would have been helpful?'

Data analysis

Data were analysed using thematic content analysis, as described by Braun and Clarke (2006). To increase knowledge about women's experiences of not receiving an embryo transfer owing to non-fertilization or poor embryo quality, an inductive approach was chosen where the analysis was data driven and not predetermined by a theory. Transcripts were entered into the data analysis software program NVivo 12 pro (QSR International LLC, MA, USA) to assist with data management.

To familiarize themselves with the data, two of the authors (H.H. and A.-L.G.) repeatedly read the whole data set, noting initial ideas and impressions. The entire data set was coded for interesting features. Initial codes were generated, first separately by each of the two authors, and then the authors together reached consensus about the meanings of codes related to the aim of the study. All codes were collated into preliminary themes and finally, after removing overlapping themes and bringing similar themes together, master theme, main themes and underlying themes were defined. A thematic map was generated to check if the themes worked in relation to the coded extract and the entire data set. An ongoing analysis refined the specifics of each theme and the overall story the analysis told, generating clear definitions and names for each theme. Each time the thematic structure was refined, all transcripts were re-read to ensure that data were accurately and comprehensively represented. The detailed analysis was conducted by the two researchers (H.H. and A.-L.G.), followed by continuous discussions through the whole process to ensure important themes were not missed and that there was adequate support in the data for the identified themes. The data analysis process ran parallel with recruitment of study participants until saturation was reached, i.e. when no new data were obtained in the interviews.

Ethical approval was obtained from the Ethics Committee of the University of Gothenburg (Dnr. 257-17).

Results

The analysis identified one master theme; *Lost and lonely*, which embodies the overall experiences organized in the two main themes; *Experiences of the event* and *Perception of needs from healthcare providers* including eight underlying themes (Table II). Each of the themes is presented by quotations from the interviewed women. At the end of each quote is the interview number from which the quote was taken.

Experiences of the event

Facing failure

The experience of not receiving the hoped-for embryo transfer was described as emotionally very complicated. The women found

Table I Characteristics of patients invited for interview after no embryo transfer and who decided to participate or not.

	Participants, n = 19	Non-participants, n = 22
Age, years mean (range)	35.1 (27–40)	34.1 (24–40)
Duration of infertility, years mean (range)	3.3 (1.5–8)	3.4 (1–8)
Cause of infertility, n (%)		
Female factor	4 (21.1)	10 (45.4)
Male factor	5 (26.3)	6 (27.3)
Unexplained factor	6 (31.6)	6 (27.3)
Mixed factor	4 (21.1)	0 (0)
Previous cycles, n (%)		
0	9 (47.4)	10 (45.5)
1–3	8 (42.1)	11 (50.0)
>3	2 (10.5)	1 (4.5)
Children in present relationship, n (%)	1 (5.3)	1 (4.5)
Country of birth, n (%)		
Sweden	13 (68.4)	16 (72.8)
Other country in Europe	3 (15.8)	5 (22.7)
Outside Europe	3 (15.8)	1 (4.5)
Education, n (%)		
College/university	16 (84.2)	9 (41.0)
Primary/secondary education	3 (15.8)	10 (45.5)
Unknown	0 (0)	3 (13.6)
Further IVF treatments planned, n (%)	16 (84.2)	19 (82.6)

Table II Overview of the master team, main themes and underlying themes identified by thematic content analysis of the women's responses during interview.

Lost and lonely	
Experiences of the event	Perceptions of needs from healthcare providers
Facing failure	To be invited for follow-up
The message	The importance of information
Prepared or not	The need of counselling
How to manage the failure	Participation in a further plan

themselves in a state when they had to prepare for both success and failure simultaneously.

All the time there's this balance. You have to pack your luggage. You have to get ready for the journey. You have to go to the airport—and then you hear that the flight is cancelled. (9)

IVF requires patients to give the treatment priority, as well as demanding strength, planning and time. Patients described their investment of emotional energy as inevitable but also potentially as the most painful and costly part of the process, affecting them strongly. The tremendous energy required to prepare for treatment made failure even harder.

Now it gets to be a strong driving force, this IVF thing. To cope with it I have to... or felt that I had to... go all the way, be all in. And, of course, that means that you run at top speed directly into a wall, when everything just stops. (6)

Several of the women had undergone previous treatments and had had to deal with negative pregnancy tests. Facing failure in terms of not receiving the hoped-for embryo transfer because of non-fertilization or poor embryo quality was described by some of them as a much worse experience than a negative test.

It feels like you have not even got to try, as if the whole treatment period is, like, in vain. You feel as if you've fallen down flat. You've put so much energy into it and you've got nothing. (8)

Receiving the message

When it has been decided that an embryo transfer will not be performed owing to poor embryo quality, the procedure at both clinics is the same—to give patients the news by phone earlier on the same day that transfer is planned.

I was sleeping when they called. 'Yes, unfortunately, it has not been...'. That first word 'unfortunately'. The rest... I don't remember anything about what she said. (7)

First reactions when receiving the message differed. Some reacted immediately with shock and despair. Others initially needed a distance

from the content of the message before facing what the bad news meant for them.

...but then despite everything I chose to stay on at work. We worked a long time that day and I was in a late meeting. Because I didn't want to go home... I didn't want to go home and be by myself. Even if Y (my partner) was home and we had decided to meet there, I didn't want to go home to my thoughts... Yes, it was a kind of a defence mechanism. Then, when I got home, I broke down. (11)

Receiving the message that no embryo transfer would take place was experienced by all women as very traumatic and for some, a crisis reaction followed.

We had some friends who knew, so I could text direct that, 'something bad has happened'. From the point of view of support, we had some friends who came round, aah, and a sister who came and made sure we ate. Because it was... we cracked up totally. (6)

Prepared or not

Most of the women were prepared for the risk of no pregnancy, but not for the risk of no transfer. Some said that they had never received any information about the possibility of no embryo transfer.

Several women had been told that some cycles ended without embryo transfer but had not realized that this could happen to them, and they were not emotionally prepared for the failure.

I read in the papers that in some cases the embryos do not develop, but I didn't know that I would be one of those. (7)

Others were completely unprepared both intellectually and emotionally.

We had no idea that they would call. It hadn't occurred to me that it could happen. I was informed that it could happen, but I did not take it in. So it was like, 'Yes I know Santa Claus is coming, but I'm not getting any presents'. Something like that. (16)

Only a few were well informed and prepared for the possibility of no transfer.

One single woman had a more rational attitude and argued that the risk of failure ought to be well known since information was given from the beginning.

Yes, it is a hard call, but very important...so that... and I think that we were prepared that this could happen. We were in the beginning, anyway. Because it says so in the information you get. So if you are totally unprepared for it I think you have not really been following. It can happen. (13)

How to manage the failure

The women initially described their experiences following no embryo transfer in terms of shock and catastrophe, followed by them devising different strategies for managing the bad news. Common for all patients was the need of a further plan representing new

possibilities. No one was about to give up on further treatment at this moment.

Patients used several approaches to make the experience more bearable and to be able to focus on further treatments. Some used problem-focused coping strategies and tried to gain a sense of control by seeking information. They also tried their own courses of action to try to improve the odds of pregnancy, such as diets and changing their lifestyle.

if we...yes. Because...yes, no, But then we said that we would perhaps wait for a bit. Because it's also ...because I'm overweight it affects the hormones and we said that we would perhaps take six months when we would, like, get a grip on our lives and try to lose weight and, like, that. So we would try to do our best before the last round (of treatment). (14)

Now we keep a very strict diet and plan to do that for three months in order to avoid fragmented embryos. (19)

Some used strategies for emotional coping and tried to process their feelings and reactions.

The key factor to coping is, after a few days, to stop seeing yourself as a victim. You cannot keep on thinking like that. (19)

Others searched for comfort in thinking about a higher perspective, believing that the event had a wider meaning.

I am the kind of person that accepts everything and thinks that perhaps there is something behind it. I am not religious or... I just think that there must be a meaning for everything. (17)

One woman faced the thought of a future without children and started a journey towards an acceptance of that possibility.

We have agreed that if nothing comes of this maybe we should have other plans for the future, travel some more or... (a little laugh). (17)

Others could not consider the possibility of a future without children.

I don't know what we'll do if nothing happens. (18)

Of the 19 patients in the study, 13 had thoughts about other alternatives such as adoption or egg donation. The option of donation was the final alternative for several, however, emotionally complicated.

When should you give up? That is so difficult. Perhaps that's why I don't feel ready for egg donation. (15)

Even if women were initially negative about egg donation, the attitude became more positive after the embryo transfer procedure did not take place. The driving force to build a family was stronger than the need for the genetic link with their own gametes.

Perceptions of needs from healthcare providers

To be invited

A follow-up meeting was of the utmost importance to all participants. The need for support means that after failed treatment women should be offered an early follow-up appointment with a doctor, without having to take the initiative themselves. This face-to-face appointment for a medical follow-up should include information about what went wrong and information about new alternatives.

Clinics often expect patients themselves to make a follow-up appointment with a doctor instead of inviting the patient to a consultation. Some of the women described the whole situation as so emotionally exhausting that they did not have the strength to take the initiative themselves by phoning for an appointment.

...that the responsibility doesn't lie with you in that situation. For then the feeling is completely different—that someone cares or just that you are seen and that, 'Now things didn't go you wanted, but there is' ...yes. (2)

Several women wished they had been offered a follow-up appointment with a doctor at the same time they received the bad news on the telephone. In this way, they would have had an appointment to look forward to, and if it was not suitable they could have made a new appointment themselves.

...shouldn't have to arrange it all yourself. It should be organised for you. If I can't make the appointment time, then it's up to me to call and rebook. (10)

Others wanted to come to the clinic on the same day they got the bad news about the transfer because they felt that they had a pre-booked time that day anyway, originally intended for embryo transfer.

When we got the bad news on the phone, they could have said, 'You can come to the appointment. We won't have so long, we won't have time to talk for an hour or so, but you can come for quarter of an hour and we can tell you what has happened and what is going to happen' and so on. (9)

It was important for the women interviewed to receive an appointment quite soon after the non-transfer and not have to wait for months. Some of the women found the delay before a new appointment quite painful.

A telephone call was all we got when our lives had collapsed. 'Come back in one and a half months'. (6)

The importance of information

All women wanted information about what went wrong and new ways to proceed. Several of the participants mentioned the lack of information received in conjunction with the treatment failure and the

frustration in not getting an answer that could explain why the treatment failed.

As I said, we still don't know why nothing happened. And that... I really want to know. It all feels unfinished. (18)

Some of the patients received thorough information from their treatment providers, and they expressed how valuable this was to them.

So the conversation with the doctor today was really important to me, just to get answers to all the questions I have been carrying round with me all those weeks since the end of January. (1)

All patients stated that they wanted clear and honest information, but the way the women wanted the information presented differed. Many expressed the need for information to be delivered in an understanding, sensitive way. A few women who had been through many earlier treatments wanted the simple facts delivered without too much emotion.

We have been in this game for so long that we want to be more like, 'Okay, what are the facts now? What went wrong?' or 'What are you saying in concrete terms?' Because when there is too much emotion I try as hard as I can not to break down, and if the person on the other side of the desk says things like, 'Ohhhh, dear me', you know, it gets really hard for me to keep it together so I'd rather keep things factual like, 'What happened?' (19)

The need for counselling

Information about counselling was usually given at the first consultation when patients were generally focused on starting treatment. Some women contacted the psychologist themselves, a contact they felt was a lifeline.

I think that the psychologist is great, but I do miss not getting any... I had to find her myself. I didn't get any information about her existence. So I do think they could have been a bit more informative, that there is support available too. (11)

The majority of the women interviewed had not received information from fertility staff about the possibility of contacting a psychologist or counsellor after the event. Several said that they had never received any information from staff about possible psychological help.

There was nothing. There wasn't even a note, 'If you need to contact a psychologist you can call this number'. I don't know how they think you could manage that. (6)

Participation in a further plan

The women described the experience of not receiving an embryo transfer as feeling as if they had fallen out of the system.

Sometimes you feel like you are following a standard template and if you don't follow it then it's like, 'What do we do now?' There's like, no plan to follow. (1)

After this experience, all the women expressed a great need for further plans, as well as a wish to be involved in this planning.

... more actively making a plan together. Like, maybe, 'What do you think?', 'Do you want...?' Well, I don't know... some kind of follow-up afterwards. Because it... I didn't know it would be so tough. (18)

The need for individual solutions was mentioned by several women. What is right for one person is not necessarily right for another.

People want different things. It is not possible to have a template...no... like 'we always do this'. Because I mean, some people think this is the best way and others want a different way. So it's probably important to have a dialogue about this. (11)

Discussion

The results of this study show that participants experienced an overall feeling of being 'lost and lonely', both when it came to their experience of no embryo transfer and their subsequent need for support. The situation was described as a shock for which they were unprepared. Their needs for contact with healthcare providers, and for information and support, were not met. The women described the event as feeling that they had fallen out of the system and left in a void without any plan to hold onto. The overall question was: What now? All women interviewed expressed a need for a further plan for managing the failure.

The need for support from healthcare providers may be met by an invitation to a follow-up meeting with a doctor, where patients do not need to take the initiative themselves. The follow-up meeting should contain information about the reason their treatment failed and prospects for a further plan.

These needs are in line with the results of another study investigating needs and assessment of fertility care among infertile men, finding the needs to be detailed information, face-to-face communication, and to be involved in further plans (Sylvest et al., 2016).

Receiving the information that the embryo transfer would not take place was, almost without exception, a shocking experience. Surprisingly, the majority of the women interviewed were not prepared for this possibility. Some women mentioned that they were never informed about the risk of no embryo transfer; others admitted that they had received the information without considering that it related to them. This illustrates the challenge concerning communication between professional health care providers and patients when it comes to giving and receiving negative information. The patient can have overly optimistic expectations, and find absorbing undesirable information difficult. Physicians, on the other hand, can find it difficult to maintain a balance between being too negative or too positive in their treatment prognoses (Klitzman, 2018).

Needs and requests for psychosocial support have been discussed in the literature. Previous studies have found requests for counselling to be few among IVF patients still in treatment. A suggested reason for this is that patients wish to avoid confronting the possibility of future failure and retain the hope for a successful outcome (Glover et al., 2009). In contrast, the results of this study find that

several of the interviewed women expressed a great need for counselling and psychosocial support, despite continuing to hope for success and wishing to go on with further treatments. Another study proposes that women do not seek psychosocial support simply because psychosocial services are not offered and information about available services are not provided by IVF clinics (Read *et al.*, 2014). These results are in line with our findings where a majority of the women said that they had not received any information about psychological support after the experience of no embryo transfer. When experiencing a highly distressing and uncontrollable event, emotional support is helpful, while in less distressing situations information and practical support help the patient take control over the situation (Read *et al.*, 2014). Not being able to go through with embryo transfer was for the majority of the women in the present study a traumatic and unexpected experience and needed to qualify for psychological support.

Constructing narratives can be emotionally supportive when processing a stressful situation (Glover *et al.*, 2009), and some women gave as the main reason for participating in this study the need to tell their own stories. After the interview, all women expressed a feeling of relief.

The results of the present study did not show that unsuccessful treatment, in terms of no embryo transfer, was a reason for dropping out. All women interviewed were planning for new treatments. In contrast, an analysis from the German IVF Registry found the failed embryo transfer to be a reason for discontinuation of treatment in 10% of all drop-out patients in the last cycle (Kreuzer *et al.*, 2018). A French study, investigating medical factors associated with early IVF discontinuation among 5135 couples, found that couples who did not experience embryo transfer in their first IVF cycle were more likely to discontinue treatment early (Troude *et al.*, 2014). Several other studies have found the psychological burden of unsuccessful treatments in terms of no pregnancy a reason for dropping out of further treatment (Olivius *et al.*, 2004; Smeenk *et al.*, 2004; Brandes *et al.*, 2009; Gameiro *et al.*, 2012; Domar *et al.*, 2018). One likely reason that none of the women interviewed intended to discontinue further IVF treatments could be that only women intending to continue with new treatments agreed to participate in this study. However, when investigating the women invited to participate in the study, we found the vast majority in both groups (participants and non-participants) intended to continue with further treatments. On the other hand, the number of women participating in this study was too small to investigate if the experience of no embryo transfer because of failed embryo development affects discontinuation of further treatment.

An overall impression from the interviews regarding the period after the non-transfer was the lack of a systematic plan for further patient care and further proposals for treatment. The women expressed a need for more extended support and service than was offered by their fertility clinic. In a model of patient-centred infertility care, Dancet *et al.* (2011) divided the dimensions identified as important for patients into *system factors* and *human factors*. The results of the present study reveal a deficiency in both system factors and human factors. System factors, such as the organization for handling these events, were regarded by some patients as a catastrophe. Human factors include emotional support by a psychologist or a counsellor given at a time of emotional emergency, but there is also a need to train the staff in communication skills, especially concerning how to deliver bad news. Responding to the frustration of a patient who wants an explanation

of why the treatment failed can be problematic for professionals when the reason is unknown. Klitzman (2018) argues that training physicians and other healthcare providers to help patients develop realistic expectations, and supporting patients experiencing treatment failures, are both necessary. Healthcare providers need to gain a deeper insight into patients' views, to be able to understand, support and assist patients after a treatment failure and ensure patient-centred care (Cunningham and Cunningham, 2013). The results of the present study where treatments did not turn out to be as expected highlights the need for patient-centred care. The results are in line with several studies advocating the importance of developing patient-centred care and shared decision-making (Verhaak *et al.*, 2007; Dancet *et al.*, 2010; Silva and Machado, 2010; Gameiro *et al.*, 2013; Bailey *et al.*, 2017; Duthie *et al.*, 2017; da Silva *et al.*, 2020).

Some important limitations to this study need to be discussed. First, the focus of the study was on the individual experience and only women participated, although the experience of not receiving embryo transfer affects both partners in a couple. By interviewing only one partner, important information about the dyadic experience was lost, as well as a more complex portrait of the partner's perspective (Read *et al.*, 2014). A few partners felt excluded when not invited to participate in the study, and the problem of partners not being included to the same extent is a known problem in fertility care (Schanz *et al.*, 2005; Malik and Coulson 2008; Arts *et al.*, 2011, 2012; Holter *et al.*, 2014b). On the other hand, when interviewing couples together, individuals may be inhibited from sharing experiences as they may give a mutually agreed view (Glover *et al.*, 2009).

This qualitative study aims to report the experiences, thoughts and day-to-day reality of specific participants, and not to generalize. Nevertheless, some aspects in this study need to be mentioned. The over-representation of a female factor in the non-responding group raises the question of whether a female factor itself signals an increase in emotional stress. The educational level also differed between the two groups, with an over-representation of a college/university education in the responding group. The majority of the participants were from the public clinic and only four women from the private clinic participated. Only one woman had children in her present relationship, so the possible impact of the reproductive history may have been lost. These aspects could all have an impact on women's experience of the non-transfer, and ought to be further investigated.

In total, 19 women (46.3%) of the 41 invited agreed to participate in the study. The women who declined participation might have described other experiences associated with not receiving an embryo transfer and had other needs for support from healthcare providers. However, a considerable number of those declining to participate did so because of emotional stress. This suggests that, in the already stressful process of IVF treatment, not receiving embryo transfer is a very traumatic event, which in turn underlines the importance of this study.

The interviews were conducted in two clinics in Gothenburg, and the experience may differ in other parts of Sweden or in other countries. However, according to the results of the national surveys, we may expect that the experiences presented in this study are transferable to other clinics in Sweden. Further research into the experience of no embryo transfer in a wider context outside Sweden is required as well as the narratives of partners and couples. The prospect of no child intensifies the infertility crises (Verhaak *et al.*, 2007) and the

question of whether the experience of no embryo transfer has a long-term effect on the coping abilities of the infertility crises itself ought to be investigated.

In conclusion, the findings of this study reveal narratives of emotional suffering connected to the experience of not receiving embryo transfer, because of non-fertilization or poor embryo quality, and a need for patient-centred care. The need for support is expressed as a wish to be offered an early face-to-face appointment for information about what went wrong, new treatment alternatives and, for many women, information about counselling. Fertility clinics should consider developing improved services and routines promoting individualized care for these patients, thereby meeting the needs expressed by the patients.

Authors' roles

The study was designed by H.H., A.-L.G. and C.B. The interviews were provided, analysed and interpreted by H.H. and A.-L.G. The original manuscript was drafted by H.H., A.-L.G. and C.B. All authors critically reviewed and revised the manuscript and approved the final version.

Funding

The study was funded by grants from the Swedish state under the agreement between the Swedish government and the county councils, the ALF-agreement (ALFGBG-70940). It was also funded by the Local Research and Development Board for Gothenburg and Södra Bohuslän (VGFOUGSB-866771) and by Hjalmar Svensson's Research Foundation (HJSV-2017012).

Conflict of interest

The authors have no conflicts of interest to declare.

References

- Arts JWM, Faber MJ, van Empel IWH, Scheenjes E, Nelen WLDM, Kremer JAM. Professionals' experience of their patients' experience with fertility care. *Hum Reprod* 2011;**26**:1119–2011.
- Arts JWM, Huppelschoten AG, van Empel IWH, Boivin J, Verhaak CM, Kremer JAM, Nelen WL. How patient-centred care relates to patients' quality of life and distress: a study in 427 women experiencing infertility. *Hum Reprod* 2012;**27**:488–495.
- Bailey A, Ellis-Caird H, Croft C. Living through unsuccessful conception attempts: a grounded theory of resilience among women undergoing fertility treatment. *J Reprod Infant Psychol* 2017;**35**:324–333.
- Boivin J, Andersson L, Skoog-Svanberg A, Hjelmstedt A, Collins A, Bergh T. Psychological reactions during in-vitro fertilization: similar response pattern in husbands and wives. *Hum Reprod* 1998;**13**:3262–3267.
- Brandes M, van der Steen JOM, Bokdam SB, Hamilton CJCM, de Bruin JP, Nelen WLDM, 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**:3127–3134.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101.
- Cipolletta S, Faccio E. Time experience during the assisted reproductive journey: a phenomenological analysis of Italian couples' narratives. *J Reprod Infant Psychol* 2013;**31**:285–298.
- Cunningham N, Cunningham T. Women's experience of infertility—towards a relational model of care. *J Clin Nurs* 2013;**22**:3428–3437.
- da Silva SM, Place JM, Boivin J, Gameiro S. Failure after fertility treatment: regulation strategies when facing a blocked parenthood goal. *Hum Fertil* 2020;**23**:179–185.
- Dancet EAF, Nelen WLDM, Sermeus W, De Leeuw L, Kremer JAM, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. *Hum Reprod Update* 2010;**16**:467–487.
- Dancet EAF, Van Empel IWH, Rober P, Nelen WLDM, Kremer JAM, D'Hooghe TM. Patient-centred infertility care: a qualitative study to listen to the patient's voice. *Hum Reprod* 2011;**26**:827–833.
- Domar AD, Rooney K, Hacker MR, Sakkas D, Dodge LE. Burden of care is the primary reason why insured women terminate in vitro fertilization treatment. *Fertil Steril* 2018;**109**:1121–1126.
- Duthie EA, Cooper A, Davis JB, Schoyer KD, Sandlow J, Strawn EY, Flynn KA. Conceptual framework for patient-centered fertility treatment. *Reprod Health* 2017;**14**:114. doi: 10.1111/186/s12978-017-0375-5
- Gameiro S, Boivin J, Dancet E, de Klerk C, Emery M, Lewis-Jones C, Thorn P, Van den Broeck U, Venetis C, Verhaak CM et al. ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction—a guide for fertility staff. *Hum Reprod* 2015;**30**:2476–2485.
- Gameiro S, Boivin J, Peronace L, Verhaak CM. Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. *Hum Reprod* 2012;**18**:652–669.
- Gameiro S, Canavarró MC, Boivin J. Patient centred care in infertility health care: direct and indirect associations with well-being during treatment. *Patient Educ Couns* 2013;**93**:646–654.
- Glover L, McLellan A, Weaver SM. What does having a fertility problem mean to couples? *J Reprod Infant Psychol* 2009;**27**:401–418.
- Holter H, Sandin-Bojö A-K, Gejervall A-L, Wikland M, Wilder-Larsson B, Bergh C. Quality of care in an IVF programme from a patient's perspective: development of a validated instrument. *Hum Reprod* 2014a;**29**:534–547.
- Holter H, Sandin-Bojö A-K, Gejervall A-L, Wikland M, Wilder-Larsson B, Bergh C. Patient-centered quality of care in an IVF-programme evaluated by men and women. *Hum Reprod* 2014b;**29**:2695–2703.
- Karaca N, Karabulut A, Ozkan S, Aktun H, Oregul F, Yilmaz R, Ates S, Batmaz G. Effect of IVF failure on quality of life and emotional status in infertile couples. *Eur J Obstet Gynecol Reprod Biol* 2016;**206**:158–163.
- Klitzman R. Impediments to communication and relationships between infertility care providers and patients. *BMC Women's Health* 2018;**18**:84.

- Kreuzer VK, Kimmel M, Schiffner J, Czeromin U, Tandler-Schneider A, Krussel J-S. Possible reasons for discontinuation of therapy: an analysis of 571071 treatment cycles from the German IVF Registry. *Geburtshilfe Frauenheilkd* 2018;**78**:984–990.
- Malik SH, Coulson N. The male experience of infertility: a thematic analysis of an online infertility support group bulletin board. *J Reproduct Infant Psychol* 2008;**26**:18–30.
- Olivius C, Friden B, Borg G, Bergh C. Why do couples discontinue in vitro fertilization treatment? Cohort study. *Fertil Steril* 2004;**81**: 258–260.
- Read SC, Carrier M-E, Boucher M-E, Whitley R, Bond S, Zelkowitz P. Psychosocial services for couples in infertility treatment: what do couples really want? *Patient Educ Couns* 2014;**94**:390–395.
- Rockliff HE, Lightman SL, Rhidian E, Buchanan H, Gordon U, Vedhara K. A systematic review of psychosocial factors associated with emotional adjustment in *in vitro* fertilization patients. *Hum Reprod Update* 2014;**20**:594–613.
- Schanz S, Baeckert-Sifeddine IT, Braeunlich C, Collins SE, Batra A, Gebert S, Hautzinger M, Fierlbeck G. A new quality of life measure for men experiencing involuntary childlessness. *Hum Reprod* 2005; **20**:2858–2865.
- Schmidt L. Infertility and assisted reproduction in Denmark. Epidemiology and psychosocial consequences. Doctoral Dissertation in Medical Science, University of Copenhagen, 2006.
- Silva S, Machado H. Uncertainty, risks and ethics in unsuccessful in vitro fertilisation treatment cycles. *Health Risk Soc* 2010;**12**: 531–545.
- Smeenk JM, Verhaak CM, Stolwijk AM, Kremer JM, Braat DM. Reasons for dropout in an in vitro fertilization/intracytoplasmic sperm injection program. *Fertil Steril* 2004;**81**:262–268.
- Sylvest R, Krogh Furbringer J, Schmidt L, Pinborg A. Infertile men's needs and assessment of fertility care. *Uppsala J Med Sci* 2016; **121**:276–282.
- Troude P, Guibert J, Bouyer J, de La Rochebrochard E. Medical factors associated with early IVF discontinuation. *Reprod Biomed Online* 2014;**28**:321–329.
- Verhaak CM, Smeenk JM, Evers AWM, Kremer JAM, Kraaijmaat FW, Braat DDM. Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Hum Reprod Update* 2007; **13**:27–36.
- Verhaak CM, Smeenk JM, van Minnen A, Kremer JAM, Kraaijmaat FW. A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment cycles. *Hum Reprod* 2005;**20**:2253–2260.
- Volgsten H, Skoog Svanberg A, Ekselius L, Lundkvist Ö, Sundström Poromaa I. Risk factors for psychiatric disorders in infertile women and men undergoing *in vitro* fertilization treatment. *Fertil Steril* 2010;**93**:1088–1096.