Reproductive choices in women with poor ovarian reserve and recurrent miscarriages
Musters, A.M.

Citation for published version (APA):
Musters, A. M. (2012). Reproductive choices in women with poor ovarian reserve and recurrent miscarriages

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)

Download date: 02 Dec 2018
Supportive care for women with unexplained recurrent miscarriages; patients’ perspectives

Anna M. Musters
Elsbeth F. Taminiau-Bloem
Emmy van den Boogaard
Fulco van der Veen
Mariëtte Goddijn

Human Reproduction 2011;26::873-7
Abstract

BACKGROUND Supportive care is currently the only ‘therapy’ that can be offered to women with unexplained recurrent miscarriage (RM). What these women themselves prefer as supportive care in their next pregnancy has never been substantiated. Therefore the aim of this study was to explore what women with unexplained RM prefer as supportive care during their next pregnancy.

METHODS We performed explorative, semi-structured, in-depth interviews. The interviews were performed with 15 women with unexplained RM who were actively seeking conception. All interviews were conducted by telephone. The interviews were fully transcribed and two researchers independently identified text segments from the transcribed interviews and categorized them in the appropriate domain.

RESULTS Women identified 20 different supportive care options; 16 of these options were preferred for their next pregnancy. Examples of the preferred supportive care were early and frequently repeated ultrasounds, βHCG monitoring, practical advice concerning life style and diet, emotional support in the form of counselling, a clear policy for the upcoming 12 weeks and medication. The four supportive care options that were not preferred by the women were admittance to a hospital ward at the same gestational age as previous miscarriages, Complementary Alternative Medicine, ultrasound every other day and receiving supportive care from their general practitioner.

CONCLUSIONS Our study identified several relevant preferences for supportive care in women with unexplained RM. Many of these can be offered by the gynaecologist and will help in guaranteeing high-quality patient-centred care.
Introduction

Recurrent miscarriage (RM), defined as two or more miscarriages before 20 weeks pregnancy, affects approximately 3% of all couples (Regan and Rai, 2000). Current diagnostic procedures identify aetiological factors, such as translocations, antiphospholipid syndrome, endocrine disorders and uterine abnormalities in approximately 50% of these couples. The other 50% are diagnosed as couples with unexplained RM (Rai and Regan, 2006). Unexplained RM is a distressing condition for the affected couple and a frustrating problem for the clinician, as there is no effective therapy for these couples. In addition to the grief that accompanies a miscarriage, anxiety is a common response during a next pregnancy (Cordell and Thomas, 1997; Cote-Arsenault, 2001; Brier, 2004; O’Leary, 2004; Bennett et al., 2005; Fertl et al., 2009).

Supportive care is frequently offered to women with unexplained RM, reporting live birth rates up to 85% (Javert, 1954; Stray-Pedersen and Stray-Pedersen, 1984; Liddell et al., 1991; Clifford et al., 1997; Brigham et al., 1999). Current guidelines from the European Society of Human Reproduction and Embryology (ESHRE) and the Royal College of Obstetricians and Gynaecologists (RCOG) recommend supportive care during the next pregnancy for women with unexplained RM (RCOG, 2003; Jauniaux et al., 2006), suggesting it has a beneficial effect.

Nevertheless, there are several problems with implementing this recommendation. First, supportive care for women with unexplained RM is an ill-defined concept (van den Boogaard et al., 2011). Second, no uniform treatment protocol can be distilled from studies on supportive care, because the care offered in these studies varied widely from early ultrasound investigation during the next pregnancy, to relaxation tapes and admittance to the hospital ward on the same gestational age as previous miscarriages (Javert, 1954; Stray-Pedersen and Stray-Pedersen, 1984; Liddell et al., 1991; Clifford et al., 1997, Brigham et al., 1999). Third, what the women themselves prefer as supportive care in their next pregnancy has never been substantiated.

Therefore, the objective of this study was to explore what women with unexplained RM would prefer as supportive care during their next pregnancy.

Materials and Methods

Women were invited to participate at the Centre for Reproductive Medicine of the Academic Medical Centre in Amsterdam after the diagnostic work-up for RM had been performed.
Women were eligible if they had two or more first trimester miscarriages (≤20 weeks pregnancy), were actively seeking conception and if no aetiology could be found for the miscarriages. The eligible women were contacted by the first author. To obtain a group of women with unexplained RM that was representative for the whole unexplained RM population, we employed purposive sampling based on demographic characteristics, number of preceding miscarriages and having children.

The semi-structured in-depth interviews, which consisted of both a topic list and open questions, were designed by an expert panel consisting of a gynaecologist, a resident, two PhD students, all specializing in RM and a medical psychologist with experience in the development of in-depth interviews (Taminiau-Bloem et al., 2010; van den Boogaard et al., 2011). The topic list and the open questions were based on information acquired at expert panel meetings and supplemented with ideas from the sparse literature on this topic (Javert, 1954; Stray-Pedersen and Stray-Pedersen, 1984; Liddell et al., 1991; Clifford et al., 1997; Brigham et al., 1999). The content of the interview was then presented to the expert panel that offered their final adjustments. The translated semi-structured in-depth interview with the open questions and topic list can be found in the Supplementary data. To test the interview procedure, the final set of interview questions were pilot-tested on two women with unexplained RM.

The interview started with an open question asking the women what they preferred as supportive care during their next pregnancy, followed by a structured topic list of supportive care options on which the women could comment on (see Supplementary data for full topic list and all open questions). During the interview, women were asked if there were any other items they wanted to add to the topic list. Each new possible option of supportive care was subsequently added to this list.

When the interview was concluded, the interviewer summarized the responses to assure accuracy. When the interviews of three consecutive women did not provide new insights, i.e. when saturation was achieved, data collection was stopped (Pope et al., 2000).

Interviews took place over a 6-month period from November 2009 till June 2010. All interviews were done by telephone and took 30–60 min. The interviewer was not involved in the RM work-up or treatment to ensure objectivity. The interviews were audio-recorded and transcribed verbatim.

Study design and analysis were performed according to the established criteria for conducting qualitative research (Britten, 1995; Mays and Pope, 2000; Pope et al., 2000). Two researchers (A.M.M. and E.F.T.B.) independently identified text segments from the transcribed interviews and categorized them in the appropriate domain. After an interview had been coded by the two researchers, they discussed their findings. Any discrepancies were mutually discussed until consensus was achieved.
Ethical approval
Subjects did not undergo additional investigations nor treatment. As assessed by the Institutional Review Board (IRB), Academic Medical Center Amsterdam, the study was not subject to the Dutch 'Medical Research Involving Human Subjects Act' (meaning that no formal IRB approval was needed).

Results
Twenty women were asked to participate. Three women declined the invitation. Seventeen women were interviewed. The two pilot interviews were not used in the data analysis. Five main options were added during the interview process: to make a plan with their gynaecologist for the first 12 weeks, βHCG monitoring before ultrasound, receiving medication during pregnancy only if it is safe, miscarriage aftercare and waiting in the waiting room with visibly pregnant women (see Supplementary data for the five additions the women made to the topic list). Data saturation was achieved after 15 interviews. Quotes were taken verbatim from the transcripts of the interviews and are presented in separate sections in italic.

The median age of the women was 32 years (ranging from 26 to 39 years old). The median number of preceding miscarriages per woman was three (ranging from two to seven miscarriages) and the median gestational age of the miscarriages was 7 weeks (ranging from 5 to 17 weeks). Fourteen women had had their last miscarriage a median 5.5 months prior to the interview (ranging from 3 to 16 months); one woman was 8 weeks pregnant during the interview. Four women had one living child, all conceived prior to the miscarriages. One woman had undergone IVF due to male subfertility.

Preferred supportive care
The women identified 20 different supportive care options for their next pregnancy, in all three domains of the theoretical model. In this section, we summarize in more detail the 16 factors that were preferred by the women (Table I).

All women had the need to inform their gynaecologist that they were pregnant. The women indicated they would like to make a plan with their gynaecologist for consultations and ultrasound appointments during the first 12 weeks of pregnancy. When I go to the doctor in the beginning (of my pregnancy) I would like to discuss what we are going to do during the next couple of weeks. Patient 14 Additionally, women would like to ask for the gynaecologist’s advice concerning life style and diet to make sure that they were not harming their pregnancy in any way. The women also found it helpful if the gynaecologist could advise certain internet sites, considering the large amount of information that can be found on the internet. The women would
Table I. Preferred supportive care options for women with unexplained RM during next pregnancy (n=15)

<table>
<thead>
<tr>
<th>Domain 1: Medical supportive care</th>
<th>Domain 2: Non-medical supportive care</th>
<th>Domain 3: Other types of supportive care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make a plan for the first 12 weeks with their gynaecologist</td>
<td>From gynaecologist</td>
<td>Women prefer an increase in partner involvement</td>
</tr>
<tr>
<td>Receive advice from their gynaecologist concerning lifestyle, diet and internet sites</td>
<td>Enquire how the patient is doing and what her emotional needs are</td>
<td>The need for supportive care directly after a miscarriage</td>
</tr>
<tr>
<td>Preference of one or max two well informed gynaecologists</td>
<td>Take the women seriously</td>
<td>Feel unhappy in the waiting room with visibly pregnant women</td>
</tr>
<tr>
<td></td>
<td>Give the women the feeling they are listened to and understood</td>
<td></td>
</tr>
<tr>
<td>Receive frequent ultrasounds in early pregnancy and during symptoms</td>
<td>Counselling from social worker</td>
<td></td>
</tr>
<tr>
<td>ßHCG blood monitoring before first ultrasound</td>
<td>Experiencing supportive care from family, friends and peer groups</td>
<td></td>
</tr>
<tr>
<td>Receive medication only if it is safe for the child</td>
<td>Relaxation tools to unwind</td>
<td>Bereavement therapy for patients and explanation of bereavement levels for gynaecologists</td>
</tr>
</tbody>
</table>

appreciate a consultation and an ultrasound early on in their pregnancy, preferably right after a positive pregnancy test or when they would be sure that a viable pregnancy could be seen on ultrasound. After the first ultrasound they would like to have repeated ultrasounds every week or every 2 weeks. If they develop symptoms resembling a miscarriage all women indicated they would want to have an ultrasound. Although the women described that the time before an ultrasound appointment is very stressful, they still wanted an ultrasound for certainty and reassurance that the fetus was (still) alive.

The women preferred treatment from one gynaecologist. If more than one gynaecologist had to be involved in their care, women stated that all treating gynaecologists would have to have full knowledge of their medical history to gain the women’s trust and confidence. For most women, gender of the gynaecologist was not an issue.

“It is nice when you have one or two clinicians, it means you do not have to keep on repeating your story and you can build a trusting relationship.” Patient 2

Women stated that they would feel supported if they had ßHCG monitoring at least two times before their first ultrasound to gain confidence for this first ultrasound.

“Before 7 weeks I would like ßHCG monitoring to check if it is rising, (it) gives me peace, a good or bad ultrasound is confrontational.” Patient 4
In general, women had a reserved attitude towards medication during their pregnancy. Their concerns were mostly related to uncertainty about the medication’s safety for their unborn child. If a specific medicine was proven as safe, then the women would want this medication during their pregnancy. Women would participate in a scientific trial, emphasizing again the importance of the medication’s safety. Women’s reasons for participating were 2-fold; first to contribute for the greater good and secondly for themselves (i.e. a higher chance of a viable pregnancy that would result in a child).

“Yes, I will seize every opportunity to increase my chances. Even if the chance is low (for a good outcome), if it will not harm (my unborn child) than I would do it.”
Patient 9

Domain 2: Non-medical supportive care
Women did appreciate non-medical support from their gynaecologist in the form of asking about their emotional needs and how they were doing. Furthermore women wanted their gynaecologist to take them seriously and give them the feeling they were listened to and understood. Women emphasized that their next pregnancy would not be their first and they would like to be treated by a gynaecologist who was aware of the stress and anxiety caused by multiple miscarriages.

“That they take you seriously. You lose confidence in your body if you’re not taken seriously.” Patient 7

Women reported that they would like counselling either during their next pregnancy or after another miscarriage. Additionally, women stated the importance of being offered counselling even if they felt they did not need it at the moment. Women preferred counselling from a social worker instead of a psychologist as they perceived social workers more approachable. The women stressed that the social worker should have experience in counselling patients with RM.

“At this moment I talk with a social worker, it is pleasant. (Because of the social worker) I look at certain things with a different perspective now.” Patient 12

Women also stated that next to supportive care from their gynaecologist and paramedics, they also experienced supportive care from peer groups, family and friends. Women actively sought peer-group contact on the internet to receive understanding and support. At home women talked with family and/or friends for support. Some women stated they would appreciate structured peer-group meetings conducted by either a psychologist or a social worker.

“You feel at ease and comfortable to tell your story because they (peers) understand me.” Patient 3
Women stated that a relaxation tape would be helpful to unwind during their next pregnancy. When asked about other forms of relaxation tools (massage, yoga) women stated they might try it when offered.

“I would use a relaxation tape if offered. I am pretty stressed and I like the feeling that I can do something. However I do not know if I would do it very often.” Patient 10

Women reacted positively to the possibility of bereavement therapy, because it would give them closure and would help them to move on. Again, women thought that the therapist should have experience with RM. They also thought it would be helpful for gynaecologists to understand the different levels of bereavement women with unexplained RM experience suffer since this would increase the gynaecologists’ recognition and empathy.

“Yes, I would like that (bereavement therapy). It would have to be bereavement therapy specifically for people with RM. It is hard to understand for other people, therefore you feel less supported. It can be lonely. If you lose someone other people know, people understand. A miscarriage and pregnancy that is very real for you, is difficult to understand for others.” Patient 13

**Domain 3: Other types of supportive care**

Women would feel supported in their next pregnancy if their partner was more involved. They suggested that the gynaecologist should involve the partners more during the consultation by addressing the partner directly. It is nice when my husband is involved; it (RM) is just as frustrating for him. The gynaecologist should direct his questions not only to me but also to my husband.

“The gynaecologist can do this by asking more general questions while looking at him.” Patient 8

Women stated that aftercare was a part of supportive care that they wanted should their next pregnancy miscarry. Women wanted guidance from their gynaecologist in the form of a consultation with the opportunity to ask questions. This would help them to start with their mourning process and be able to pause before they start on their next pregnancy.

“I have had almost no guidance after my miscarriages. I would like to have the feeling that I can ask questions when I feel the need. It is a struggle to accept my miscarriages, and there is nowhere I can go to get support.” Patient 11
Sitting in the waiting room with visibly pregnant women was a major problem for women with RM. They found it very confrontational and uncomfortable. During their next pregnancy, women would prefer to avoid this situation.

“Sitting between pregnant women is a problem for me.” Patient 1

Non-preferred supportive care
Of the 20 factors we identified, four factors were not preferred by women or women found them not to be relevant.
The first supportive care options that was not preferred was admittance to a hospital ward on the same gestational age as previous miscarriages because they felt that staying in hospital would not give an extra reassurance and they would rather be at home. The second option that was not preferred was the exploration of Complementary Alternative Medicine (CAM). Women stated that they would not seek CAM in their next pregnancy. Some women simply would not think of it and others stated that they were not ‘desperate enough’. The women who were positive towards CAM said they wanted to investigate anything that might help and would prefer acupuncture. Third, women found that an ultrasound every other day would not be needed, every week or 2 weeks would be sufficient. Fourth, women would not go to their general practitioner (GP) to receive supportive care because the women stated that they did not feel comfortable discussing their RM with him or her, as their relationship with their GP was not close or they did not feel the GP had experience with women with unexplained RM.

Discussion
To delineate the so far ill-defined concept of supportive care in couples with unexplained RM, we collected data on what women with unexplained RM would prefer as supportive care in the very early weeks of their next pregnancy. Women identified 20 different supportive care options, of which 16 were preferred during their next pregnancy. The women sought these supportive care options in their next pregnancy for reassurance, comfort, certainty, trust and to feel understood and supported. As anxiety is a common response during pregnancy for women who have experienced (recurrent) miscarriage because they fear that another pregnancy loss might occur, these feelings of support and care are very important for these women and may help them to decrease anxiety.

Of the 16 different preferred supportive care options mentioned, 10 can be offered by gynaecologists. This has great implications for the gynaecologist who feels frustrated
that he or she cannot help women with unexplained RM, but can now focus on early investigations and consultations to provide practical medical advice and supportive care.

Of the 20 identified supportive care options, four were not preferred by the women. CAM and admittance to a hospital ward at the same gestational age as previous miscarriages were two of the four non-preferred supportive care options. This is in contrary to what we hypothesized during our expert panel meetings. Because of a lack of research on the preferences of women with unexplained RM concerning supportive care, this study employed a qualitative, phenomenological approach as an initial systematic and explorative description and evaluation (Patton, 2002; Leedy and Ormond, 2005). However, the performance of qualitative research has limitations. First, interpretation of interviews is vulnerable to bias. For this reason, all transcriptions of all interviews were analysed independently by two researchers who were not involved in the work-up or treatment of the women to ensure objectivity. Second, it is impossible to estimate the impact of each factor upon the preference for supportive care. This would require quantitative research and assessment of the magnitude of the factors. Third, the scope of this research was limited to the preferences of women with RM. Further research should involve the perceptions of the care givers to help categorize and prioritize the preferred supportive care options regarding feasibility and superfluity.

Nevertheless, this study supplies the clinician with information on women’s preferences and the clinician can manage expectations accordingly. Despite these limitations, we believe our work provides necessary insights into the preferred supportive care in women with unexplained RM. Quantitative research would be the logical next step to measure the supportive care options, always keeping in mind the feasibility of the preferred care.

In conclusion, our study identified several relevant preferences for supportive care in women with unexplained RM. These results can help us to make a start in guaranteeing high-quality patient-centred care. To implement specific supportive care for women with unexplained RM, a quantitative confirmation and assessment of the magnitude of the preferences is necessary, combined with an investigation of caregivers’ perceptions.
References


