

# Recurrent pregnancy loss: couples' perspectives on their need for treatment, support and follow up

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**STUDY QUESTION:** What do couples referred to or attending a recurrent pregnancy loss (RPL) clinic believe they need in terms of treatment, support and follow up?

**SUMMARY ANSWER:** Men and women wish for more information, earlier access to treatment, support and follow up that is sensitive to their history of pregnancy loss (PL), includes both members of the couple, and acknowledges the psychological impact of RPL.

**WHAT IS KNOWN ALREADY:** Previous research has highlighted women's dissatisfaction with medical care provided post-PL and their desire for medical professionals to have increased awareness about PL and recognition of the psychological impact of PL. Less is known about the needs of the male partner, the needs of those experiencing RPL and whether the needs differ during different reproductive stages.

**STUDY DESIGN, SIZE, DURATION:** Over a 2-month period in 2017–2018, 13 couples who were referred to the national RPL program in Copenhagen, Denmark were qualitatively interviewed.

**PARTICIPANTS/MATERIALS, SETTING, METHODS:** Inclusion criteria were heterosexual couples with at least three consecutive PLs before 12 weeks' gestation with no children or one child prior to the PLs, not currently pregnant, and willing to be interviewed in English. Couples were interviewed together in a semi-structured format. Data were analyzed using thematic analysis. Invitations ( $n = 30$ ) were sent to couples recently referred to the RPL program who indicated an interest in participating and 17 couples contacted the interviewer to schedule an interview. Due to cancellations, 15 interviews were held. Data from 13 interviews that met the study criteria were used for the current analysis.

**MAIN RESULTS AND THE ROLE OF CHANCE:** The participants had experienced a median of three PLs (range 3–6). Both men and women described the cumulative effect of RPL with an increase in pressure and exhaustion by the third and subsequent losses. Inclusion of the male partner in consultations and treatment was seen as important. Men felt pressured to remain positive and support their partners despite their own feelings of loss. The findings showed that couples desired reliable and accurate information about RPL. They wished for recognition from the medical community that RPL has a significant psychological impact, and stressed that effective treatment should include both members of the couple, with attention to both physical and psychological aspects of the RPL and should be tailored to their current reproductive stage, in order to help them cope with the negative impact of RPL and the anxiety associated with conception and another pregnancy.

**LIMITATIONS, REASONS FOR CAUTION:** Participants were self-selected thus findings cannot be generalized to all couples with RPL.

**WIDER IMPLICATIONS OF THE FINDINGS:** This is the first study addressing the needs of the female and male partners in couples suffering from RPL. The findings highlight a disconnect between couples' perceived needs and their experience of medical care after RPL. This may be partly due to a discrepancy in couples' and medical professionals' perceptions of the PLs. The findings highlight that medical

professionals need to take a holistic and couple-focused approach in their treatment of RPL and include attention to the psychological impact and cumulative effect of the multiple PLs on the couple. The results underscore the need for informational resources and psychological support for couples experiencing RPL, tailored to their reproductive stage.

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## Introduction

Pregnancy loss (PL) is a common occurrence in early pregnancy. A Danish register-based study found that 13.5% of pregnancies ended in PL requiring hospital admission (Nybo Andersen et al., 2000). There is no consensus regarding the definition of recurrent pregnancy loss (RPL; ESHRE, 2018), but in the Danish RPL Unit, RPL is defined as three or more consecutive PLs before 22 weeks' gestation. According to a recent study, the incidence of RPL is ~0.65%, although again this register-based study only included hospital-treated miscarriages (Rasmak Roepke et al., 2017). The true incidence is considerably higher, however, when including PL not registered at hospitals, with estimates of at least one in four pregnancies ending in PL (Macklon et al., 2002). In Denmark, standard care after PL includes a visit to the acute gynecological department where treatment focuses on emptying the uterus through medical induction or surgical removal. After three or more PLs, couples can be referred to the RPL clinic which is a national referral center that offers evaluation, diagnosis, treatment, treatment trials and supportive care to couples/individuals.

The negative psychological impact and feelings of grief and loss related to PL may intensify with multiple PLs (Brier, 2008; Bardos et al., 2015). Research shows an increase in depressive symptoms and more frequent psychiatric diagnoses in those with RPL (Toffol et al., 2013) and there are higher rates of depression and anxiety in this group compared to other women trying to conceive (Kolte et al., 2015a; 2015b). Men's experiences of RPL are virtually unexplored.

Research also shows that women with PL are dissatisfied with the medical care they receive and wish for more information, empathy, psychological support and follow up and to know the cause of the PL (Simmons et al., 2006; Musters et al., 2011; Bardos et al., 2015; Meaney et al., 2017). A recent systematic review on patients' perspectives on patient-centered care after early pregnancy complications found that PL is a significant life event and women and/or their partners desire an individualized approach to care (van den Berg et al., 2018).

RPL is a unique health issue because it is experienced by men and women individually and as a couple. However, much of the available research does not include both partners and is survey based, thus we lack a deeper understanding of the perspectives of couples with RPL and their needs. This information is essential in informing the provision of effective medical care to this group.

The question that guided this research was: what do couples referred to or attending a RPL clinic believe they need in terms of treatment, support and follow up?

## Materials and Methods

### Ethical approval

Participants provided consent to take part in the study. According to Danish law, interview studies do not require permission from a scientific ethics committee. As no personal identifying data about participants was provided to the interviewer, co-researchers or RPL unit staff, the study was not subject to the Danish Data Protection Agency requirements (no approval needed).

### Study design

This was a cross-sectional, qualitative study of 13 couples who had experienced RPL and were recently referred to or attending the RPL program in Rigshospitalet, Copenhagen, Denmark. The inclusion criteria were: (i) heterosexual couples; (ii) at least three consecutive PLs before 12 weeks gestation; (iii) no children or one child prior to the PLs; (iv) willing to be interviewed in English; and (v) not currently pregnant. We chose three consecutive losses prior to 12 weeks' gestation as a cut-off to ensure a homogenous cohort and because we specifically wanted to investigate the emotional impact and needs after early losses. Both partners in each couple were interviewed together given the lack of research on couples' accounts.

### Data collection

A nurse within the RPL clinic reviewed recently referred couples' files and sent invitations to those who met the inclusion criteria and indicated an interest in participating. The files of couples who had attended their first consultation in the RPL clinic up to four months prior to the study date and couples on the waiting list were included in the nurse's review. Couples were invited to contact the interviewer directly to schedule an interview. There were 30 invitations sent to eligible couples and 17 couples contacted the interviewer. Due to cancellations 15 interviews were held. Data from two interviews were excluded from the current analysis given that the couples no longer met the study criteria at the time of the interview (e.g. currently pregnant). Saturation of data was reached at 11 interviews.

In qualitative research, sample size is less important than data saturation. Data saturation is used as a criterion for how much data should be collected (Saunders et al., 2018) and a means of ensuring trustworthiness and soundness of the data analysis and findings. Data saturation refers to continuing to collect data (in this case through interviews) until no new information is found in subsequent interviews that leads to new themes (Saunders et al., 2018). It can also refer to when the researcher/interviewer begins to hear the same comments over and over and believes they have a full understanding of the participants' perspectives (Legard et al., 2003). In this case, it meant that after the 11th interview, the interviewer did not hear any new examples of couples' needs for treatment,

support or follow up. The decision was made to interview the remaining couples given that they had already been scheduled and wanted the opportunity to share their experience. Given that many couples highlighted that the interview was the first time they had an opportunity to share their experience in detail, it was thought that it would be most ethical to include the remaining couples in data collection. This also served as a trustworthiness check that data saturation had indeed been met.

Interviews were held in person at Rigshospitalet over a 2-month period in 2017–2018. Couples were interviewed together. Interviews ranged between 81 and 109 min (average 91 min). Interviews were conducted by the first author, a psychologist trained in qualitative research. The semi-structured interview guide included questions that were informed by a review of the literature and discussion with the multi-disciplinary bilingual team of authors (i.e. experts in the medical, psychological, public health fields). Questions explored the couples' experience of RPL, the impact on their relationship, and their perspectives on their need for treatment, support and follow up after RPL (e.g. 'What have you needed in terms of treatment, support and follow up after RPL? What services and support would be helpful?'). Interviews were transcribed verbatim by the first author. The data specific to the couples' needs for treatment, support and follow up are used in this article.

## Data analysis

A thematic analysis with an iterative process was used (Braun and Clarke, 2006). Lincoln and Guba's (2000) recommendations for trustworthiness of data analysis were implemented into the study design. Transcripts were read in detail several times by the first author/interviewer to become immersed in the data. Sections of text were extracted and labeled with a code to reflect their meaning. Another researcher reviewed the coding for two of the thirteen transcripts to ensure trustworthiness of the data analysis. Small modifications were made to the codes based on this discussion. Codes from all transcripts were compared and clustered into data-driven themes. The themes were discussed with members of the research team and changes were made based on agreement. Descriptions of themes were written using the participants' words to illustrate their meaning.

## Results

Table I presents demographic and reproductive details of the couples. Five themes were developed to highlight the couples' perspectives on their need for treatment, support and follow up. Couples' needs were specific to their reproductive stage (e.g. trying to conceive, pregnancy, during/after PL) but could be categorized within the same broad themes. Differences were primarily due to unique psychological concerns and information sought at each reproductive stage (Table II). Quotes have been extracted from the transcripts to illustrate the content of the themes (see Supplementary Table I for longer illustrative quotes).

### 'A loss every time': Need for sensitivity, empathy and supportive care

Couples wanted medical professionals providing medical care during and after PL to be aware of the emotional and psychological impact of RPL. They desired sensitivity, empathy and acknowledgment of their losses (i.e. that 'every [pregnancy] loss counts') from medical staff. They highlighted a disconnect between their perceptions of the PLs and the attitude and care of medical professionals. By the second and third PL, many participants described the sense of dread and worry that 'something must be wrong' and a growing fear they would not

**Table I** Demographics of the 13 participating couples.

Demographics	N (%)
<b>Marital status</b>	
Married couple	5 (38.5)
Common-law couple (living together)	8 (61.5)
Years in relationship (M)	8.4 (range 3–20)
<b>Age (M (SD))</b>	
Women	37.0 (3.3)
Men	38.2 (5.0)
<b>Education level</b>	
High school	1 (3.8)
Technical training	2 (7.7)
Short (<3 years)	6 (23.1)
Medium (3–4 years)	6 (23.1)
Long (+4 years)	11 (42.3)
<b>Reproductive details</b>	
Couples with child together	3 (23.1)
Number of PLs (median)	3 (range 3–6)
Months since last PL (M)	4.3 (range 1–9)
<b>Most advanced fertility treatment ever used</b>	
IVF	8 (61.5)
IUI only	3 (23.1)
None	2 (15.4)
Months on RPL clinic waitlist (M)	5.8 (range 3–9)
<b>Timing of Interview</b>	
Before consultation	5 (38.5)
Same day (after)	3 (23.1)
After consultation	5 (38.5)

PL = pregnancy loss; RPL = recurrent pregnancy loss; M = mean.

become parents (or parents to another child). They described the cumulative effect of multiple losses with a sense of exhaustion from the grief and pressure to conceive again, combined with a fear of whether they could cope with the psychological impact of another PL. The participants stressed the perceived insensitivity when hearing comments from medical professionals like it is 'just nature's way of telling you there's something wrong', 'it's common' or 'you can try again'. Couples also provided examples of insensitive comments received from medical professionals whilst receiving care for a subsequent pregnancy and highlighted their wish for sensitivity to their anxiety related to another PL.

### 'He lost something too!': Need for a couple-focused approach

Couples expressed a desire for men to be included in medical care during and after PL and for medical professionals to acknowledge that both partners are negatively impacted by RPL. Women described their need to produce a child and feelings of self-blame and guilt regarding the PLs. For example: one said: 'I can't help thinking if we had started earlier we wouldn't be having these problems'. In contrast, men

**Table II Summary of needs by theme and reproductive stage.**

Needs	Trying to conceive	Pregnancy	During pregnancy loss	Post pregnancy loss
Sensitivity, empathy and supportive care	<ul style="list-style-type: none"> <li>• Empathy regarding pressure to conceive</li> <li>• Support with decision-making</li> </ul>	<ul style="list-style-type: none"> <li>• Empathy regarding fear of another PL, anxiety and worry whilst pregnant</li> </ul>	<ul style="list-style-type: none"> <li>• Empathy and support while waiting to complete miscarriage</li> <li>• Empathy for feelings of powerlessness</li> </ul>	<ul style="list-style-type: none"> <li>• Follow up call to check on well-being and coping</li> </ul>
Couple-focused approach	<ul style="list-style-type: none"> <li>• Acknowledgment that both partners feel pressure to conceive</li> </ul>	<ul style="list-style-type: none"> <li>• Support and care to men and women during pregnancy</li> <li>• Men: feel pressure to remain positive</li> <li>• Women: feel pressure of maintaining pregnancy</li> </ul>	<ul style="list-style-type: none"> <li>• Inclusion of men and women in medical care</li> <li>• Men: feel helpless</li> <li>• Women: feel powerless, guilt, self-blame</li> </ul>	<ul style="list-style-type: none"> <li>• Inclusion of men and women in medical care as both partners experience loss</li> </ul>
Information	<ul style="list-style-type: none"> <li>• Statistics regarding success rates of treatments, i.e. live birth rates</li> </ul>	<ul style="list-style-type: none"> <li>• Common reactions</li> </ul>	<ul style="list-style-type: none"> <li>• Common physical symptoms and psychological reactions</li> </ul>	<ul style="list-style-type: none"> <li>• Causes of PL and common physical and psychological reactions and options</li> </ul>
Testing and treatment	<ul style="list-style-type: none"> <li>• Support with decision-making</li> </ul>	<ul style="list-style-type: none"> <li>• Early detection of problems with pregnancy and fetus</li> <li>• Reduced waiting period between pregnancy test and scan</li> </ul>	<ul style="list-style-type: none"> <li>• Patient-centered / driven approach</li> <li>• Many prefer access to evacuation as the fastest method of expelling fetus</li> <li>• Earlier access to tests and scans i.e. after second PL</li> </ul>	<ul style="list-style-type: none"> <li>• Examinations to determine causes</li> <li>• Discussion of treatment options</li> <li>• Provision of treatment</li> </ul>
Psychological care	<ul style="list-style-type: none"> <li>• Emotional support</li> <li>• Stress and coping strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Emotional support</li> <li>• Stress and coping strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Emotional support</li> <li>• Stress and coping strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Emotional support</li> <li>• Assistance with processing grief and loss</li> <li>• Facilitation of acceptance</li> </ul>

described their sense of helplessness to support their partner that increased with every PL. They felt pressured to remain positive and focus on solutions even though they felt a sense of loss and a fear they would not be able to have a child. Remaining positive and supporting their partner became more difficult after multiple PLs. Several of the men broke down into tears when asked in the interview how RPL had been for them. As one man said, 'It's [RPL] been the most difficult experience of my entire life. Even worse than losing my father'.

### 'We need answers': Need for information

Men and women described a desire for access to accurate and reliable information. Couples highlighted their frustration in the perceived lack of information from the medical field about RPL, which left them uncertain where to look for reliable information. They described their feelings of powerlessness after multiple PLs and how searching for answers helped them feel some control. At all reproductive stages, couples wanted information regarding what were 'normal' or common physical and psychological responses. Couples wanted information related to the causes of RPL, prevalence of RPL and treatment success rates. Several discussed how information provided after multiple PLs could assist them with decision-making about treatment and a future pregnancy.

### 'Why wait?': Need for earlier access to testing and treatment

Couples expressed their frustration with the perceived lack of follow up from the medical system after a PL. They wished for assistance and

support with developing a formal follow up plan for a future pregnancy and discussion of their treatment options. Instead, they felt dropped and forgotten by the medical system and frustrated that there was no continuity of medical care after each PL. Given their history of multiple PLs, participants also wanted earlier access to pregnancy testing and additional scanning to provide them with some peace of mind during a subsequent pregnancy. When miscarrying, several women wanted access to the fastest method of expelling the fetus. Participants wished for earlier access to diagnostic tests and treatment rather than the required three PLs. They thought it was cruel to go through the emotional pain related to a third PL before being able to seek specialized care. Couples felt precious time had been wasted waiting for a referral.

### 'Someone to talk to': Need for psychological care

Every participant spoke of experiencing grief and loss related to RPL. Both partners believed that care for RPL should include psychological treatment to provide emotional support and help them develop strategies to cope with the negative impact of RPL. They were frustrated that services were not available to them especially given the cumulative effect of multiple PLs. Psychological support was needed in the period during and after miscarrying, during a subsequent pregnancy, and when deciding whether to conceive again. Several spoke about their frustration with the strict national/municipal criteria for referral to free or subsidized psychological treatment (i.e. only if fetal death after 22+ weeks gestation). In some cases, men believed their partners would have benefited from psychological care immediately after a PL. One said this would have 'taken the pressure off' of him. In other cases,

men wished that they could access psychological care as a couple. Some believed a psychologist should be part of the medical team in the RPL clinic.

## Discussion

This study examined the needs of couples with RPL for treatment, support and follow up. The findings show that couples desire more sensitivity from medical professionals and wish to receive medical care that takes a couple-focused approach and includes earlier access to testing and treatment, the provision of information and supportive and psychological care. While the analytical themes were developed inductively they confirm the recommendations in the new ESHRE guideline for management of RPL (ESHRE, 2018). The findings are also consistent with a recent systematic review on patients' perspectives on patient-centered care after early pregnancy complications, underscoring the strong need for improving care after PL (van den Berg *et al.*, 2018).

The findings demonstrate that couples experiencing RPL have unique needs and require extra sensitivity when provided medical care, given the cumulative effect of multiple losses that takes a toll on both partners. Consistent with other studies (Wong *et al.*, 2003; Simmons *et al.*, 2006), after the second and subsequent PLs, couples did not want to be told by medical professionals it is 'just nature's way'. Instead, they desired understanding and empathic statements like 'I'm so sorry' or 'It must be incredibly difficult'. With each PL, couples described an increased sense of pressure to become pregnant again, but feared the psychological impact of another PL. When suggesting additional treatment, medical professionals should recognize that 'every loss counts' and that couples require sensitivity and support with decision-making given they may feel conflicted about trying to conceive again.

The provision of information to couples with RPL and if possible, earlier access to testing to identify causes regardless of whether intervention could have prevented it (Bardos *et al.*, 2015) could help couples cope with and reconcile the multiple PLs and if desired, bolster their energy to feel ready to try to become pregnant again.

Couples' needs also varied according to their current stage of reproduction (Table II). Differences were primarily due to unique psychological concerns (e.g. pressure to become pregnant, fear of PL during pregnancy, powerlessness during PL) and type of information sought. For example, the participants described the pregnancy period as very stressful and their desire for supportive care and extra testing and scans to alleviate their anxiety. While this is part of the treatment provided by dedicated RPL units and recommended in the new ESHRE guideline for management of (ESHRE, 2018) and by previous research (Stray-Pedersen and Stray-Pedersen, 1988), couples described a lack of access to medical care and a need for increased sensitivity and support from medical professionals suggesting that more can be done to meet couples' needs.

Our findings showed that men are negatively impacted by RPL and have unique needs for support, information and treatment. Men felt burdened by their need to be strong and to support their partner when they were also grieving. Research has shown men with severe male factor infertility experience similar pressures during fertility treatment (Sylvest *et al.*, 2018). Participants expressed their desire for both members of the couple to be included in decision-making and

treatment and acknowledgment of the psychological impact of RPL on both of them. Currently there is no professional psychological care provided by the RPL clinic in Copenhagen. Consistent with research on the role of counseling for the loss associated with infertility (Schmidt *et al.*, 2003), men and women also wished to receive support and learn strategies to increase their coping and facilitate the grieving process by a specially trained professional knowledgeable about the impact of multiple PLs.

There may be several reasons for the unmet needs identified by couples in the study. The findings suggest there is a disconnect between couples' and medical professionals' perceptions of PL. The general understanding among medical professionals is that PL is nature's way of securing that only healthy fetuses survive. As such, doctors may believe that patients should in fact be happy not to become parents to a very sick child and may underestimate the psychological impact of the PL (A. Kolte, personal communication). The couples' unmet needs may also reflect the current medical system where couples receive treatment for PL within an emergency-room type setting and often see different doctors and nurses each time. Several couples stated their wish for continuity of medical care. This is consistent with a previous study on women's preferred care after two or more PLs (Musters *et al.*, 2011) and research on couples' preferences for continuity of care during fertility treatment (Dancet *et al.*, 2010).

Only three of the couples interviewed had a child together. Our findings suggest that these couples experienced pressure to conceive, albeit for different reasons (i.e. to give their child a sibling) and had similar needs for medical care and psychological support. Future research should examine potential differences in more detail.

## Limitations

This was a self-selected sample of heterosexual couples and we cannot assume that this is the experience of all couples with RPL. For this exploratory study, we recruited couples who had recently attended their first RPL clinic consultation and couples from the waiting list. Few differences were noted between couples' needs based on the timing of the interview, likely given that those who had completed their RPL consultation had not yet begun treatment or were in the early stages. We interviewed each couple together and mutual influences may have been a factor in what was shared in the interviews, as each partner likely influences each other's perspectives. The interviewer used her training in couples' counseling to ensure both members shared their perspectives. The interviews were conducted in English which might have excluded some couples. Consistent with recommendations to address methodological challenges of cross-language qualitative research, the interview questions were developed by bilingual co-researchers and pilot-tested with the first couple interviewed (Squires, 2009). Couples provided positive feedback about speaking in English during the interview and several suggested that having an outsider (non-Danish speaker) interview them gave them more freedom to share their experience.

## Conclusion

This is the first qualitative study addressing the needs of couples experiencing RPL. The findings highlight a disconnect between the couples' perceived needs and their experience of medical care after

multiple PLs. This may be partly due to discrepancies in the couples' and medical professionals' perceptions of PL and a lack of recognition of and sensitivity to the emotional impact of RPL by medical staff. Men are negatively impacted by RPL and feel pressure to remain positive and support their partner. A couple-focused and holistic approach is needed when providing medical care to couples with RPL, addressing the psychological impact and cumulative effect of multiple PLs on both men and women. There is a need for the development of information resources and psychological support for couples experiencing RPL that is tailored to their reproductive stage in order to help them cope with the negative impact of RPL and the anxiety associated with another pregnancy.

## Supplementary data

Supplementary data are available at *Human Reproduction* online.

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## Authors' roles

All co-authors contributed to the concept and design of the study and the analysis/interpretation of the data, and critically revised and provided final approval of the article. E.K. conducted the interviews and drafted the initial version of the article.

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## Conflict of interest

None declared for all authors.

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