# Preterm Premature Rupture of the Membranes (PPROM): a study of patient experiences and support needs

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# Abstract

## Background

Preterm prelabour rupture of membranes (PPROM) is a common obstetric condition but outcomes can vary depending on gestation. Significant maternal and fetal complications occur including preterm birth, infection, abruption, cord prolapse, pulmonary hypoplasia and even death. Although the need for psychological support is recognised it is unclear how much is actually offered to women and their families. This study aimed to survey the views of women and their families who have undergone PPROM in order to understand the care and psychological burden these families face.

## Methods

An online survey was conducted, recruiting women via social media with collaboration from the patient advocacy support group Little Heartbeats. Responses were collated where fields were binary or mean and standard deviations calculated. Framework analysis was used to identify and analyse themes in free text responses.

## Results

180 PPROM pregnancies were described from 177 respondents. Although care was variable and respondents were from across the world there were common themes. Five themes were highlighted which were: a lack of balanced information regarding the condition, support in decision making and support with the process, specific psychological support and ongoing psychological consequences of PPROM.

## Conclusion

This survey highlights areas in which care needs to be improved for women with PPROM. Previous studies have shown that providing good care during the antenatal period reduces long term psychological morbidity for the whole family.The need for support, with regard both to information provided to women and their families and their psychological support needs to be addressed urgently.

## Keywords

Preterm prelabour rupture of membranes; preterm birth; perinatal; mental health; psychological support

## Introduction

Preterm prelabour rupture of membranes (PPROM) is a condition where rupture of the membranes occurs prior to 37 weeks of pregnancy. Overall PPROM complicates 3% of pregnancies in the United Kingdom(Mercer, 2003). This amounts to approximately 20,400 deliveries every year.

PPROM often presents diagnostic and management challenges for clinicians and this in turn can be an extremely distressing time for patients and their families. In 50% of cases labour starts within one week of membrane rupture(Thomson, Royal College of, & Gynaecologists, 2019).  Where spontaneous labour does not occur in women who PPROM at 24+ weeks and where there is no overt evidence of infection, an individual delivery plan can sometimes be deferred until 37 weeks’ gestation in order to mitigate the effects of preterm birth(Thomson et al., 2019). When women PPROM under 24 weeks there is no guidance on the optimal time to deliver, which can often lead to confusion as to best practice("ACOG Practice Bulletin No. 188: Prelabor Rupture of Membranes," 2018). When delivery occurs very preterm, neurodevelopmental, gastrointestinal and respiratory sequelae can be substantial(Ward & Beachy, 2003). However, poor outcomes are not universal.

In addition to the effects of prematurity, PPROM presents additional risks to both the mother and baby. While poor outcomes are not universal, rupture of membranes may lead to sepsis, placental abruption and cord prolapse, whilst early oligohydramnios may result in pulmonary hypoplasia, arthrogryposis y(Thomson et al., 2019). Maternal and fetal mortality rates are also increased. The most significant adverse outcomes are inversely correlated with the gestation at membrane rupture(Goodfellow et al., 2023; Pasquier et al., 2005). Approximately 0.1% of pregnancies are complicated by membrane rupture prior to 24 weeks’ gestation(Linehan et al., 2016) and these pregnancies are at the highest risk of both maternal and fetal morbidity and mortality, and present specific counselling and management conundrums for clinicians. In addition, in cases of second trimester PPROM, clinicians offer women the option of termination of the pregnancy due to the high risk of pulmonary hypoplasia, and high risk of associated neonatal mortality if the infant survives(Muris et al., 2007). Although morbidity associated with pulmonary hypoplasia secondary to second trimester PPROM is over 50%(Laudy & Wladimiroff, 2000; Lauria, Gonik, & Romero, 1995), prognosis is not uniformly poor(Farooqi, Holmgren, Engberg, & Serenius, 1998). Recent data from UKOSS indicates that of all women that ruptured their membranes prior to 23 weeks’ gestation in the UK over an 18-month period, 30.7% made the decision to terminate the pregnancy and 69.3% elected to continue(Goodfellow L, 2023).

Support with decision making and managing uncertainty, including information giving has been found to be helpful for women with high-risk pregnancies (Hendrix et al., 2023; Schmuke, 2019). This is likely to be acute for those with PPROM; some will make extremely difficult decisions as to whether to terminate wanted pregnancies, while others are exposed to potentially prolonged periods of uncertainty regarding both their health and that of their baby (Bendix, Hegaard, Bergholt, & Langhoff-Roos, 2015; Muris et al., 2007) . The impact of PPROM, both physical and psychological is therefore immense and often protracted.

Pregnancy complications are known to be associated with increased psychological morbidity(Fairbrother, Young, Zhang, Janssen, & Antony, 2017), and high rates of anxiety, depression and post-traumatic stress have been noted in those who experience negative obstetric events(Malouf et al., 2022) and pregnancy loss(Quenby et al., 2021). Although the Royal College of Obstetricians and Gynaecologists Greentop Guideline on the management of PPROM after 24 weeks highlights the significant psychological burden these women and their families face(Thomson et al., 2019), mental health support is often not routinely offered to them and the best form of support is uncertain.

This study aimed to survey the views of women who have gone through PPROM in order to understand their experiences and support needs.

## Methods

An online survey was undertaken for women or those close to them who had experienced PPROM. Where respondents had experience of more than one pregnancy affected by PPROM they were given the option to complete the form separately for each affected pregnancy.

The patient advocacy organisation for women and families affected by PPROM, ‘Little Heartbeats’, was used to advertise the survey via social media and Little Heartbeats website, hosted by the platform ‘Qualtrics’. A link to the survey was posted for a three-month period from March – June 2022. The survey was undertaken anonymously and participants provided informed consent prior to commencing. Completion took approximately 30 minutes. Signposting was provided on the survey page to psychological support should participants experience psychological distress following participation in the study. These included: Little Heartbeats, The Birth Trauma Association, Make Birth Better, Improving Access to Psychological Therapies (an NHS England initiative to which patients can self-refer), and a Clinical Psychologist who was part of the study team.

Ethical approval was obtained from The Health Faculties Research Ethics Subcommittee King’s College London (ref: HR-21/22-24775). Consent to participate was indicated by completing the anonymous survey.

Questions were devised with the aid of a series of focus groups hosted by Little Heartbeats. Specific questions and topics were developed to capture the key aspects of the experiences of PPROM from identification to post pregnancy. Questions were tailored for four groups of respondents depending on the situation that they had experienced. These were: group 1 - those whose pregnancy was complicated by PPROM but their baby had survived, group 2 - those whose baby had died following a decision to continue with the pregnancy after PPROM, group 3 - those whose were not able to continue the pregnancy for medical reasons (for example significant maternal sepsis) and for whom no decision had been possible and group 4 - those who decided not to continue with the pregnancy and elected for termination. Initial questions were generic to all four study groups and then separate tailored questions were filtered dependent on groups. The survey questions can be seen in the supplementary material.

The complete survey comprised background questions about demographics (age, ethnicity), details of PPROM pregnancy and pregnancy history, closed and open free text questions about the experience of recognition of PPROM, diagnosis by professionals, decision making about the pregnancy, support during the pregnancy and birth/labour and finally support following the pregnancy. This paper reports background information, categorial questions regarding information, decision making and wellbeing, and analysis of open responses charting respondents’ perspectives of what they found helpful and unhelpful during their PPROM pregnancy and their recommendations for women experiencing PPROM.

The primary research question was: ‘What do women find helpful and unhelpful during their experience of PPROM?’ The secondary research question was: ‘What could be improved in the support for women experiencing PPROM?’

## Data analysis

Survey results were imported from Qualtrics into Excel. Where fields were binary or categorical (eg study group) percentages were calculated and where continuous, mean and standard deviation were calculated.

To analyse free text responses, framework analysis was used(Ritchie J, 1994). This method was chosen as it allowed examination of themes across respondents, groups and situations. There are five stages involved in analysing the data through framework analysis: familiarisation; identifying a framework; indexing; charting and mapping and interpretation.

An initial process of familiarisation took place with three members of the study team (FC, ZS and CZ) reading the survey responses. Deductive codes from focus group discussions and relevant literature and inductive codes from free text responses were then generated and discussed. Final codes were entered into a database. These codes were then applied to the data and a matrix of responses from the dataset was generated. From this, themes were generated, which were checked and discussed with the research team for coherence and representativeness.

We organised the data both according to the outcome of the PPROM pregnancy and according to whether it had occurred before or after 24 weeks (at which point medical management may alter, for example termination is not offered for PPROM alone beyond 24 weeks gestation). As a general guide, themes were categorised as ‘very frequent’ if mentioned by more than half of respondents, ‘frequent’ if a quarter to a half, ‘occasional’, if a quarter or less (a third in group 4), did not occur or ‘not applicable’. Final themes and subthemes and categories were checked for sense by an advisory group of women with lived experience who did not suggest any further changes.

## Results

Over the study period 179 participants (describing 182 pregnancies) responded to the online survey. Three people completed the survey twice. 111 were from the UK and Ireland, 53 from North America, nine from Europe, five from Australia, two from New Zealand, one from Africa. Only two respondents had not directly experienced PPROM and their data was excluded for this analysis, leaving the total as 177 individuals/180 pregnancies, all women who had gone through PPROM.

Of respondents, 125 had a surviving baby, 39 had continued with the pregnancy but the baby did not survive, 13 had lost their baby and no decision about this had been possible due to the urgency of the medical context, and three had chosen to terminate the pregnancy. 125 had a PPROM pregnancy before 24 weeks, with the remaining 55 after 24 weeks. All respondents completed the full survey. Free text data was provided by 56-93% of participants depending on the specific question.

The demographics of respondents in each study group and pre/post 24 weeks can be seen in Table 1.

 *Table 1 about here*

Women were asked some binary questions on whether and how information was given to them. About a third to a half of women in any group received any information on PPROM, with less than 7% receiving written information overall. Women were not routinely contacted for debrief after PPROM, and overall 38% felt they were not asked about their own wellbeing at all during the process. This also applied to 38% of women who had PPROM before 24 weeks. Of 170 responses given, 75 (44%) reported prior psychological problems, while 132 (77.6%) reported experiencing difficulties after PPROM. Table 2 shows the responses to the quantitative questions relevant to psychological impact.

*Table 2 about here*

A coding framework was derived and five overall themes were highlighted (see Table 3). The frequency of the theme in participants responses across groups was then derived using a coding matrix. Themes were checked with the research team including people with lived experience.

**(1) The importance of clear, balanced information**

About half of the participants highlighted the importance of having the range of outcomes explained in a clear, factual and compassionate manner. Where this had occurred, respondents found it very helpful in all groups. The opposite experience was also highlighted in some cases. Several women felt that they did not receive any information at all; more information seemed to have been given to women whose babies survived. Some commented on the need for written information to return to in their own time, and how difficult it was to process the news. Some noted that their medical teams were not well informed about PPROM and how to manage it.

 “*My doctors were great and explained what was happening and some reasons why it could be happening as we didn’t know at the time. They explained it was probably PPROM and what that meant*” [Group 1: PPROM 18 weeks]

*“Too much information to comprehend and no certainties of outcomes. No reason for this happening and no information on if it could happen again.”* [Group1, PPROM 18 weeks]

For women who had experienced PPROM before 24 weeks it appeared that these themes were more prominent than for those after this point, with the focus being on risks, and a sense of lack of information.

**(2) Support and respect for decision making**

Most women in the three applicable groups where a decision was possible had the option of termination discussed with them. However, pressure to terminate was noted by some respondents in all groups. Not being told that a positive outcome was possible was a cause of distress for many women. This theme came up for some participants in response to questions about both diagnosis and management.

 “*The doctors just gave all reasons to end pregnancy. Had to look online for ways to try to keep it going.”* [Group 1. PPROM 20 weeks]

*“Constant pressure to end pregnancy and no regards for my choices, no information given, lack of proper check ups*” [group 2, PPROM 18 weeks]

Women experienced PPROM at different stages of the pregnancy, necessitating different management plans. However, those who felt involved in the process and were supported where there was a decision to be made felt that this was helpful. Comments on the need for information to make an informed decision came through in women with PPROM before 24 weeks. Women in Group 1 often described having no real decision to make (in that they wanted to continue) but some had experienced pressure to make a decision quickly or one that they did not agree with. Women in Group 2 described pressures on their decision making and some also noted that false hope was very difficult. Those in Group 4 all had different experiences, with some feeling they did have space to make their decision. Women across groups wanted more information and more of a sense that they were at the heart of the decision-making process. Having ‘as long as I needed’ was important for those where a decision had been possible.

*“We were given the options and they supported our decision to carry on with the pregnancy”* [Group 1, PPROM 20 weeks]

*“I felt dictated to not provided with options”* [Group 1, PPROM 33 weeks]

“ *The fact that they were very frank but also very sympathetic was exactly what we needed. All that was unhelpful was the fact that it was out of everyone’s control*” [Group 3, PPROM 29 weeks]

**(3) Being supported through the process**

Women found compassionate responses from the treating team to be particularly helpful and conversely those that had experienced a lack of empathy or said that they were not listened to had experienced the process as very traumatic.

*“It was approached very sensitively and I appreciated that”* [group 3, PPROM 17 weeks]

There was a focus on medical input or lack thereof in Group 2, with some women reporting being left to themselves to manage the situation at home. Several would have liked more input from the medical team. This also came through for women who had experienced PROM before 24 weeks. Women in different groups wanted more consultant input in general.

*“They couldn’t tell me why it happened or if my baby would make it just that I had to “wait and see”* [Group 2, PPROM 15 weeks]

Continuity of care was highlighted as being important by women in several groups, with about half of women in group 1 mentioning that they received this. This was mentioned more by women with PPROM over 24 weeks. Differing opinions and management within teams was unhelpful. When it came to managing bereavement, midwives were often highlighted as very helpful and supportive. In group one, regular medical support and check-ups were often mentioned as helpful. Several women described the lack of interventions available before the 24-week cut-off as very difficult, whether or not their pregnancy had progressed to this point.

*“It was just a do as you have been until you reach viability then we can maybe help you.”* [Group3, PPROM 20 weeks]

Even though the experiences were different in each group, women across groups appreciated information about medical procedures and what was going to happen or could happen. For those experiencing loss, care away from labour wards was also important.

**(4) Specific psychological support**

There was a sense of lack of emotional support for women across the sample, with more mention of signposting and seeking online support from women with PPROM before 24 weeks. Only about half the women in Group 1 where their babies had survived were asked about their own wellbeing during PPROM. Women who experienced baby loss were more consistently asked but offers of or direction to formal support were relatively uncommon. Those women who mentioned that they had interacted with neonatal intensive care (NICU) often mentioned a psychologist, but for others NHS referrals were often not made, there were barriers in accessing or it was not clear how to refer. Some in Group 1 did not feel that they required additional support, but the majority did. Those experiencing bereavement were more likely to have been signposted to help but often had mixed experiences, especially with non-specialist help. Acknowledgement of the impact of PPROM on anxiety and where relevant loss and grief was helpful. Conversely, lack of empathy made a difficult situation more tough.

“*The hospital had someone check in. But honestly the nurses, doctors and massage therapist were the best therapy.”* [Group1, PPROM 21 weeks]

“*Being told every day that baby may not make it even though I was doing everything I could was mentally draining and scary. No support was given with regards to my mental state and I was suffering with severe anxiety*” [Group 1, PPROM 25 weeks]

**(5) Ongoing impacts**

Most (about 70%) of group 1 and almost all in the other groups self-reported ongoing issues with anxiety, depression and/or PTSD. For some the initial months were worst, while many others described enduring effects and difficult times such as if there are ongoing medical complications for their child, or anniversaries for those that have lost a child. Pregnancies subsequent to PPROM were difficult, especially if women had not received support for mental health. Some women in all groups said they would not consider further pregnancies after their experiences. There was a similar pattern across all groups by outcome and by the time of PPROM.

“*It’s been a year and I still have [symptoms]”* [group 2, PPROM 23 weeks]

Women in all groups described impacts on partners – sometimes directly in terms of stress and relationship difficulties and ongoing uncertainty about the future. Partners were often removed from the process of care which was difficult for all. Separation from other children was also a consequence of the management of PPROM.

“*It put a lot of stress on my partner and family. My partner felt like he had to pretend everything was ok*” [Group3 PPROM 18 weeks]

*Table 3 about here*

**Recommendations for other women experiencing PPROM**

Women were asked at various points in the survey what they would recommend for others experiencing PPROM. There were clear themes in the recommendations from women across groups. These themes were consistent with the strengths and deficiencies women had reported in their own care.

* Well informed medical teams
* What the early signs are and information on what to do
* Comprehensive information, including some statistics on survival
* Compassionate discussion of all the options and respect for the woman’s decision
* Psychological support during and after PPROM
* Continuity of Care
* Psychological and specialist obstetric support in future pregnancies

## Discussion

This survey is the first to document women’s perspectives of PPROM. Common themes which were highlighted include a lack of provision of balanced information regarding the condition, compassionate support with decision making and the need for psychological support throughout and beyond PPROM, with little formal support being currently provided.

Almost all respondents to this survey highlighted the need for more information, preferably given in a compassionate discussion, and the importance of patients’ views being at the heart of decision making. They also highlighted a preference for additional information in written form, with signposting to further information, other relevant sources and specific PPROM support. Indeed only 50% of respondents felt that were provided with any information regarding the condition at all. This undoubtedly compounded the psychological effects. Lack of information and knowledge was prominent for women experiencing PPROM before 24 weeks. A natural tendency is to search for health advice online, particularity when there is a paucity of information received from healthcare professionals(McMullan, 2006). A recent study has indicated that the information available to women online on PPROM is limited and often poor quality(Hall M, 2023). The US Office for Disease Prevention and Health Promotion reported concern regarding the emotional risk online information can present(Services, 2010).

It is uncertain whether this lack of information was due to information not being given by care providers in the first place or whether this was due to recall and being overwhelmed with processing the situation. A number of respondents highlighted that they did not feel that medical staff were sufficiently knowledgeable about the condition and that positive information should be presented in addition to that on adverse outcomes. This does highlight a need for further training and consistency of medical advice.

A theme that clearly emerged from this sample is that women felt that they were not given accurate, balanced information, and few received anything in written format. It is well documented that the amount of information correctly recalled by patients in a medical setting is limited(Godwin, 2000). 40-80% is immediately forgotten and the amount recalled is inversely proportionate to the amount of information provided(McGuire, 1996). PPROM is a particularly worrying and complex condition which can result in multiple outcomes dependent on multiple confounding factors, such as gestation, the presence of infection and the possibility of associated complications such as cord prolapse and placental abruption. Consequently, the amount of information to convey is large. Three explanations for this poor level of recall have been purported: use of terminology and acronyms by the clinician, the mode of information, written versus verbal;, and factors related to the patient such as expectations, language barriers and educational level(Ley, 1979). The use of medical acronyms was noted by some women who were told their waters had broken, but the acronym ‘PPROM’ was not explained to them by clinicians. There is diverse terminology used in PPROM and therefore this is a particularly pertinent issue for the women affected. Furthermore, many women reported being overwhelmed and unable to take information in, welcoming the chance for the opportunity to have follow up discussions where this occurred. Only 6.7% of respondents reported being provided with written information in this survey.

Although teaching of communication skills is a focus for both undergraduate and recently qualified postgraduate doctors(Fallowfield & Jenkins, 2004), not all senior doctors received this during their training. It has been reported that sensitive care received at the time of perinatal bereavement can alter how parents process the event and how they grieve(Downe, Schmidt, Kingdon, & Heazell, 2013; O'Connell, Meaney, & O'Donoghue, 2016). A lack of sensitivity can leave a lasting impact(Nuzum, Meaney, & O'Donohue, 2017) but conversely when care is provided with compassion this have an extremely positive impact (Erlandsson, Saflund, Wredling, & Radestad, 2011; Kelley & Trinidad, 2012; Nuzum et al., 2017). This was mirrored by our survey among women who suffered bereavement as well as those who did not.

This survey indicated that a strong theme for women was their report of experiencing a large psychological impact as a consequence of PPROM. This was the case for women experiencing PPROM before and after 24 weeks and across outcomes. Almost all respondents also reported important impacts on their partner (where applicable). They felt that there was a legacy of anxiety, traumatic stress, grief and depression following the experience. This needs to be investigated with robust longitudinal studies using diagnostic tests due to the risks of over-reporting using self-report alone. However, the results are in accordance with previous work which highlighted that women with PPROM are more likely to experience antenatal anxiety and postnatal depression. A previous retrospective study by Zemstov et al 2022 assessed 132 women who had been admitted for PPROM over a six-year period. Overall 18.9% of women developed postpartum depression. Earlier gestational age at membrane rupture and neonatal morbidity/mortality were significantly associated with postpartum depression(Zemtsov et al., 2022). However, in regression models only a history of depression and neonatal morbidity remained associated with postpartum depression. Women in our survey mentioned a broader range of impacts including anxiety and PTSD which need more robust investigation. Although our study was larger, the fact it was an online survey meant that respondents were a self-selecting group.

Although The Royal College of Obstetricians and Gynaecologists recognises the psychological impact of those affected by PPROM and national guidelines highlight the importance of psychological support for women affected by PPROM(Thomson et al., 2019) this survey indicates that few were offered or able to access this. Appropriate psychological support during traumatic events can reduce the development of long-term sequelae such as post-traumatic stress disorder(Ford & Ayers, 2011). The quality of support during birth (and related experiences) is likely to impact on subsequent maternal mental health and is therefore an important target for improved care and prevention. Given the high rates of self-reported PTSD in this sample, women who have experienced PPROM should be screened for PTSD and their psychological health in future pregnancies should be carefully assessed. This should apply for women with PPROM before and after 24 weeks and regardless of the outcome.

There was large disparity in the sizes of the groups, with many more women participating who had not experienced loss of their baby (125 v 55). The sample size was low for women who had baby loss, particularly those who had opted to terminate their pregnancy, likely reflecting the psychological complexity of this situation and the difficulties in reflecting on it. (González-Ramos, Zuriguel-Pérez, Albacar-Riobóo, & Casadó-Marín, 2021). The results in these groups should therefore be interpreted with further caution.

Recommendations from respondents were consistent with the themes of what they found helpful or unhelpful in their care. These were primarily about information and support in decision making and ongoing support and psychological care, regardless of the obstetric outcome. In particular, support with planning future pregnancies and during subsequent pregnancies was highlighted, as well as involvement and support for partners at all stages. These recommendations could be more generally applicable to women with other severe complications of pregnancy such as pre-eclampsia or fetal malformations. Future research could usefully explore the commonalities and specific needs across groups.

## Strengths and Limitations

This is a relatively large study surveying care of women with PPROM with 177 respondents, reporting on experiences of 180 pregnancies. However, many thousands of women experience this condition annually in the UK alone and this smaller international sample may not be representative, meaning that results may not be generalisable. The survey was designed in collaboration with patients with experience of the condition. Our sample was drawn from a wide geographical area and international management protocols may differ. There are likely issues with the representativeness of the sample: a pre-requisite to answering the study was the ability to speak English to a certain standard and have access to a computer. Previous studies have highlighted these issues as being a significant barrier to communication and potentially women from under-represented groups may face even more challenges than those such as language and online access already highlighted. The respondents were also not reflective of all women experiencing PPROM, with the majority in our sample being Caucasian. It is well recognised that pregnancy outcomes are worse for women from ethnic minorities(Knight M, 2022). Consequently, to truly understand the impact of PPROM, efforts must be made to include all ethnic groups in future research, also using interpreters and translated materials where possible (Lovell, Silverio, Story, Skelton, & Matthew, 2023).

In addition, participants of this survey possibly had high rates of self-reported pre-existing mental health problems (45% in the sample overall, in contrast to 25-40% of adult women [29]). Furthermore, the mean gestational age for PPROM was relatively low in all groups, possibly suggesting that the survey was completed by women who may have had particularly difficult experiences. The diagnosis of PPROM was self-reported. It is therefore possible that the women choosing to participate in the survey were a self-selecting group.

Conclusions

This survey highlights the harrowing journey for many women and their families who have experienced PPROM with gestations below and above 24 weeks of pregnancy, and how aspects of their care could be improved to ease the psychological impact. Better information, consistency of care and compassionate support with decision making by medical providers are key recommendations. Research around how obstetric professionals can best to support the wellbeing of pregnant women choosing to continue their pregnancy in the context of PPROM would be helpful (Blaylock, Trickey, Sanders, & Murphy, 2022). Psychological support should be considered for women and should be easily accessible both for women and their families, both during and after PPROM. Further work is required to assess what format this support should take and its consequence on longer term psychological health. Future studies should collaborate with women with lived experience to design the most appropriate interventions for those who are going through, and who have experienced PPROM.

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Table 1: Demographics of respondents and baseline characteristics

|  |  |  |
| --- | --- | --- |
|  | **Grouped by outcome** | **Grouped by timing of PPROM** |
|  | **Group 1****Baby survived****(n=125)** | **Group 2****Continued with the pregnancy but baby did not survive****(n=39)** | **Group 3****No decision was possible****(n=13)** | **Group 4****Chose to end the pregnancy****(n=3 )** | **Before 24 weeks****N=125** | **After 24 weeks****N=55** |
| **Age of respondent range****Mean (sd)** | 21-4532.94 (5.34) | 24-4734.85 (5.13) | 26-4032.85 (3.67) | 26-3230.00 (3.46) | 24-4733.46 (5.14) | 21-4532.91 (5.40) |
| **Age at time of PPROM Mean (sd)** | 31.16 (5.40) | 32.31 (5.00) | 31 (4.22) | 29.67 (4.04) | 31.5 (5.04) | 30.76 (5.48) |
| **Number of pregnancies complicated by PPROM****1****2****3****>3** | 116901 | 3431- | 94-- | 3--- | 112111- | 485-1 |
| **Ethnicity (n,%)****White****Asian****Mixed/multiple****Black (African, Caribbean, British)****Other** | 113 (90.4)2 (1.6)6 (4.7)2 (1.6)2 (1.6) | 29 (72.5)2 (5.0)3 (7.5)4 (10.0)1 (2.5)- | 10 (76.9)1 (7.7)2 (15.4)00- | 3 (100)0000- | 104 (83.2)5 (4.0)8 (6.4)5 (4.0)2 (1.6) | 50 (90.9)-3 (5.5)1 (1.8)1 (1.8) |
| **Number previous pregnancies** **Range****Median** | 1-112 | 1-113 | 1-63 | 1-32  | 0-143 | 1-112 |
| **Assisted conception (yes) (n, (%)** | 14 (11) | 5 (12.8) | 0 (0) | 1 (33.3) | 16 (12.8) | 3 (5.5) |
| **Gestation at time of PPROM** | 11-3623.24 (6.05) | 13-3320.25 (3.97) | 15-2919.04 (3.93) | 14-1917.24 (2.93) | - | - |
| **Outcome (n,%)**Baby survivedContinued: lossNo choice Terminated  |  |  |  |  | 74 (59.2)36 (28.8)12 (9.6)3 (2.4) | 51 (92.7)3 (5.5)1 (1.8)0 |

Table 2: quantitative survey responses

|  |  |  |
| --- | --- | --- |
|  | **Grouped by outcome** | **Grouped by timing of PPROM** |
|  | **Group 1****Baby survived****(n=125)** | **Group 2****Continued with the pregnancy but baby did not survive****(n=39)** | **Group 3****No decision was possible****(n=13)** | **Group 4****Chose to end the pregnancy****(n=3)** | **Before 24 weeks****N=125** | **After 24 weeks****N=55** |
| **Information given re PPROM n (%)****Written****Verbal****Other (e.g. signposted to website)** | 68 (54.4)10584 | 19 (48.7)1181 | 8 (61.5)170 | 1 (33.3)010 | 53 (42.4)6 (4.8)52 (41.6)3 (2.4) | 33 (60.0)6 (10.9)31 (56.4)2 (3.6) |
| **Balanced information given?****No****Yes** | 75 (61)48 (39) | 33 (87)5 (13) | n/a- | 3 (100)0 | 81 (72.3)31 (27.7) | 30 (57.7)22 (42.3) |
| **Only negative information (n,%)****No****Yes** | 63 (52)59 (48) | 9 (24)29 (76) | -n/a | 03 (100) | 33 (29.5)79 (70.5) | 39 (76.5)12 (23.5) |
| **Contacted for debrief n(%)****No****Yes** | 102 (85)18 (15) | 19 (49)20 (51) | 4 (30)9 (70) | 1(33)2 (66) | 83 (67.5)40 (32.5) | 43 (82.7)9 (17.3) |
| **Asked about your wellbeing n (%)****Not asked****Asked but superficial****Yes** | 47 (44)12 (11)49 (45) | 12(33)4(11)20(56) | 2(16)-10(83) | --3(100) | 39 (34.8)9 (8.0)64 (57.1) | 22 (46.8)7 (14.9)18 (32.7) |
| **Signposted for help n (%)****No****Psychologist****Support group or third sector****Bereavement midwife****Yes but declined****No but did not require this** | 74 (73)20 (20)1 (1)1 (1)4 (4)2 (2) | 19 (50)3 (8)8 (21)4 (11)4 (11)- | 2 (17)5 (42)3 (25)-2 (17)- | -3 (100)---- | 63 (56.8)23 (20.7)12 (10.8)5 (4.5)8 (7.2)- | 33 (73.3)8 (17.8)--2 (4.4)2 (4.4) |
| **Past psychological problems n (%)****No****Yes** | 71 (61)46 (39) | 15 (41)22(59) | 7 (54)6(46) | 2(66)1(33) | 60 (48%)65 (52%) | 32 (58%)23 (42%) |
| **Mental health afterwards (self report) n (%)****No problems****Anxiety****Depression****Anxiety and Depression****PTSD** | 36 (31)18 (15)6(5)28 (24)30 (25) | 1(3)2(6)5 (14)17 (46)12 (32) | 1 (8)--7 (58)4 (33) | ----3 (100) | 26 (22.2)10 (8.5)7 (6.0)41 (35.0)33 (28.2) | 12 (22.6)10 (18.9)4 (7.5)14 (26.4)13 (24.5) |
| **Offered support in subsequent pregnancies n (%)****No****Yes****N/A** | 39 (32)22 (18)60 (20) | 13 (34)16 (42)9 (24) | 2 (15)10 (77)1 (8) | 1 (50)1 (50)- | 36 (29.8)38 (31.4)47 (38.8) | 19(35.8)11 (20.8)23 (43.4) |

Notes: % not including missing data

Table 3: Themes and subthemes from free text responses

|  |  |  |
| --- | --- | --- |
|  | **Grouped by outcome** | **Grouped by timing of PPROM** |
|  | **Group 1** | **Group 2** | **Group 3** | **Group 4** |  |  |
| **Themes**Subthemes | Baby survived | Continued: Baby loss | No choice | Termination | **Before 24 weeks** | **After 24 weeks** |
| **Importance of clear, balanced information** |  |  |  |  |  |  |
| Only risks mentioned | \*\* | - | - | \* | \*\* | - |
| Minimal information given | \*\* | \*\* | \* | \* | \*\*\* | \* |
| Not written | \*\* | - | \*\* | \* | \* | \* |
| Too much to process at the time | \*\* | \*\* | \* | - | \* | - |
| Lack of information on why | \* | \*\* | \*\* | \*\* | \* | \* |
| Lack of information on PPROM | \*\* | \*\* | \*\* | \*\* | \*\* | \*\* |
| **Support and respect for decision making** |  |  |  |  |  |  |
| Pressure to terminate | \*\*\* | \*\* | N/A | \*\* | \*\*\* | \* |
| False hope given | - | \*\* | - | - | \* | - |
| Information to make informed decision | \*\*\* | \*\*\* | \*\*\* | \*\*\* | \*\*\* | \*\* |
| Peer support and testimonials | \*\* | \*\* | \*\* | - | \*\* | \* |
| Kindness | \*\* | \*\* | \* | \* | \* | \*\* |
| Time to make a decision | \*\* | \*\* | N/A | \* | \*\* | \*\* |
| **Being supported through the process** |  |  |  |  |  |  |
| Staff kindness and compassion | \* | \*\* | \*\*\* | \* | \*\* | \* |
| Focus on medical intervention only | \*\* | \*\* | \*\* | - | \*\* | \*\* |
| More and sooner consultant care | \*\* | \*\* | \*\* | \* | \*\* | \* |
| Lack of support and information | \*\* | \*\*\* | \* | \*\* | \* | \* |
| Continuity of care | \*\* | \* | - | - | \* | - |
| Management away from labour ward | \* | \*\* | - | - | \* | - |
| **Specific psychological support** |  |  |  |  |  |  |
| Regular emotional check in | \* | \*\* | \*\*\* | \*\*\* | \* | \* |
| Signposting | \* | \* | \*\* | \*\*\* | \*\* | \* |
| Finding online support | \*\* | \*\* | \*\* | \* | \*\* | \* |
| **Ongoing impacts** |  |  |  |  |  |  |
| Mental health | \*\* | \*\*\* | \*\*\* | \*\*\* | \*\* | \*\* |
| Subsequent pregnancies | \*\*\* | \*\*\* | \*\*\* | \*\*\* | \*\*\* | \*\*\* |
| Impact on partners and family | \*\*\* | \*\*\* | \*\*\* | \*\*\* | \*\*\* | \*\*\* |

\*\*\*: very frequent theme (> ½ respondents); \*\*: frequent theme (1/4 to 1/2 respondents); \*: occasional theme’(>1/4) -: did not occur; N/A not applicable.