Women's experiences of three early miscarriage management options

a qualitative study

Lindsay F Smith, Julia Frost, Ruth Levitas, Harriet Bradley and Jo Garcia

ABSTRACT

Background

Miscarriage affects around one in six pregnancies. Much research has taken place identifying the consequences of this for parents but is mainly quantitative. Of the limited qualitative studies, none have explored women's experiences of the methods of miscarriage management received.

Aim

To assess the social and personal impact of different management methods (expectant, medical and surgical) on women's experience of first trimester miscarriage.

Design of study

Qualitative interviews using a topic guide with a purposive cohort of four categories of women (each management method plus non-participants) 6 months to 1 year after first trimester miscarriage. Focus groups with both research participants and health workers.

Setting

Women from three hospitals in the South West of England that participated in the Miscarriage Treatment (MIST) trial.

Method

Seventy-two interviews were undertaken between September 1999 and June 2000. There were also five focus groups (47 participants) and two feedback sessions (8 participants) with written feedback from 12 women. Interviews lasted 0.5–2.5 hours generating over 2000 A4 pages of transcripts. The transcripts were analysed for common themes, using standard proformas, which were filled in by individual team members and then discussed by the whole research team. Iterative readings in the light of new emerging issues ensured that new themes could be identified throughout the analytical process. All transcripts were then encoded for the identified themes using NUDIST.

Results

Common themes emerged across all management options although some were specific to just one or two management options. The five major themes arising out of the data analysis were: intervention; experiences of care; finality; the 'baby'; and pain and bleeding.

Conclusions

Women's experiences and beliefs vary widely and their preferences need to be considered in their early miscarriage management. The three methods have different benefits and problems from the women's point of view. Competence and caring from professionals are especially important.

Keywords

life experiences; miscarriage; quality of health care.

INTRODUCTION

Miscarriage is common, affecting around one in six pregnancies.¹ Over the last 20 years there has been much psychological and medical research exploring the consequences of early miscarriage indicating that responses can include grief, anxiety, depression, stress, guilt, self-blame, relationship problems and even suicide.²-6 These effects can last at least up to 2 years.²-10

General work on women's health¹¹⁻¹³ has explored the historical processes by which pregnancy and childbirth were transformed into events under medical care, with births taking place in hospital. Such work has often been critical, advocating, on the whole, a less interventionist approach. But other research suggests that many women welcome the reassurance offered by medical expertise and technological aids, ^{14,15} although family support is crucial and medical responses are often considered inadequate. ^{16,17}

However, most of this body of research has been of a quantitative nature, involving the application of a range of standardised anxiety scales and health measures. Many authors¹⁸⁻²² point to the need for more qualitative research to illuminate the experience of miscarriage and its effects because, for example, psychological scales indicate levels of anxiety but do not reveal exactly what is the focus of

LF Smith, MD, FRCP, FRCGP, GP, East Somerset Research Consortium, West Coker, Somerset. J Frost, PhD, research associate in primary health care, Academic Unit of Psychiatry; H Bradley, BA, PGCE, BSc, PhD, senior lecturer in sociology; R Levitas, BSc, PhD, Department of Sociology, University of Bristol, Bristol. J Garcia, BA, MSc, Social Science Research Unit, Institute of Education, London.

Address for correspondence

Lindsay F Smith, East Somerset Research Consortium, Westlake Surgery, High Street, West Coker, Somerset BA22 9AH. E-mail: Research@esrec.nhs.uk

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such anxiety. Only one qualitative study has explored this issue²³ and it did not distinguish between surgical and medical methods and did not include any longer-term follow-up.

There was therefore a need for qualitative research to explore women's experiences of early miscarriage, to improve their care and to understand the social and personal impact. The miscarriage treatment (MIST) trial²⁴ (Petrou S, Trinder J, Brocklehurst P, Smith LF, unpublished observations, 2005) provided an ideal and unprecedented chance for such an investigation. It offered a pre-existing sampling frame of women identified medically as experiencing missed or incomplete miscarriage from which a qualitative sample could be drawn. The project aimed to explore a number of issues related to women's experiences of early miscarriage; this paper reports their experiences of the different methods of management (expectant, medical and surgical).

METHOD

The research recruited women who were linked to the MIST trial, of which one author was the principal investigator. This randomised controlled trial compared three different management methods (expectant, medical and surgical) of failed first trimester pregnancies (less than 13 weeks' gestation). For the trial, women were recruited from the early pregnancy assessment clinics of several hospitals and then randomised to one of the three methods of management. Surgical management involved general anaesthetic and a short operation to empty the womb; medical management involved giving drugs to encourage the womb to contract and empty itself; expectant management involved waiting for the womb to empty spontaneously. The MIST trial recruited 1200 women between May 1997 and December 2001²⁴ (Petrou S, Trinder J, Brocklehurst P, Smith LF, unpublished observations, 2005).

The core of the qualitative study was semistructured interviews with women recruited to the trial and another group of women who had decided not to participate in the trial. Women were recruited from three of the seven trial recruitment centres (Southmead and St Michael's Hospital in Bristol and the Royal United Hospital in Bath). Women were informed of the research when they were contacted 8 weeks after miscarriage (when they received the last trial paperwork) and re-approached 6–12 months later, enabling those who wished to opt out to do so.

The initial topic guide had been approved by the project advisory group (Box 1). Most interviews were carried out by one of the authors with fewer than 10% being undertaken either jointly or solely by two other experienced qualitative interviewers. Women were interviewed in their homes, the interviews taped and

How this fits in

It is well documented that early miscarriage is a distressing experience for women and their partners. This paper reports the findings of a qualitative study assessing the social and personal impact of the different management methods (expectant, medical, surgical) on women's experience of first trimester miscarriage. Women (and their partners) need to receive appropriate information about the management options available to them and have their views taken in to consideration when choice of treatment is made.

subsequently transcribed verbatim. Where women expressed a preference for being interviewed with their partner, a friend, or a relative, this was respected due to the potentially distressing nature of the research. The interviews, once anonymised, were analysed using the NUDIST qualitative analysis package. The analysis involved a process of close iterative readings. Transcripts were shared between the five members of the research team. Each interview was read individually and summaries produced on a proforma: demographic and treatment details were recorded along with what were identified as potential themes or issues of significance. After a batch had been completed the whole team read the summaries and discussed them at a meeting and a set of themes were then included on subsequent proformas. Subsequent transcripts were read looking for more on these themes, but this did not preclude the identification of new themes. The discussions guided the development of the topic guide for later interviews. Transcripts were also subjected to iterative readings by the team to ensure that no major issues had been overlooked. The key themes identified were subsequently used to encode all the transcripts using NUDIST.

Provisional findings were presented to two feedback groups of women who had been interviewed and five focus groups of healthcare professionals including trial recruiting nurses. Both types of groups

Box 1. Initial topic guide.

- ▶ Demographic details (age, social class as indicated by own and partner's occupation, marital status, number of children, family situation, ethnicity and nationality);
- previous reproductive history and experience;
- history of the recent miscarriage;
- experience of the mode of management and of other related healthcare services;
- support from family, doctors and midwives;
- ► feelings before and after miscarriage;
- subsequent feelings;
- effects on partner and other family members;
- coping strategies; and
- future reproductive hopes and plans.

were facilitated by the authors and recorded and transcribed. A short report of the main findings was also sent to all the women who had participated. They were invited to offer any written comments and also to attend feedback meetings if they wished to do so. The responses of those various group discussions also contributed to the writing of the final report.

RESULTS

Interviews (seven pilot, 72 main (20 surgical, 18 medical, 18 expectant, 16 non-participants in trial) occurred between September 1999 and June 2000; transcription and analysis were finished by June 2001 and focus groups (47 participants) and feedback sessions (eight participants; plus written feedback from another 12) by December 2001. Demographic details of interviewees are in Table 1.

The length of the interviews varied from 30 minutes to 2.5 hours. On the occasions where women had forgotten specific details, or where they wanted to emphasise how they felt at the time of the miscarriage, many drew on accounts that they had written in personal diaries, at the time of the miscarriage.

Principal themes

Among the principal themes relevant to a comparison

Table 1. Characteristics of participar	its.
Characteristic	n
Management method	

Characteristic	n	Total
Management method		
Surgical	20	
Medical	18	72
Expectant	18	
Non-participant	16	
Age (years)		
15–19	0	
20–24	1	
25–29	22	
30–34	24	72
35–39	20	
40–44	3	
45–50	2	
Class		
Working	25	
Lower middle	27	72
Middle	15	
Upper middle	5	
Ethnicity		
White	71	72
Other	1	
Reproductive history		
One or more previous successful pregnancy	50	
One or more previous termination	6	
One or more previous miscarriage	26	
One or more previous stillbirth	2	
One or more subsequent miscarriage	10	
Pregnant at time of interview	2	
Subsequent successful pregnancy	2	

of the methods of management that emerged from the data were: intervention; pain and bleeding; experience of caring; finality; and the 'baby'.

Intervention

Women in all three management groups expressed views in two areas related to intervention. First, there were many comments about the issue of whether intervention was appropriate or not. The majority of women who mentioned this queried whether there was any need for intervention at all:

'I didn't want a D & C [dilation and curettage], I didn't ... I know it sounds silly, 'cos the baby was already dead, but I don't agree with abortion, and things like that, and to me it felt the same; I wanted to do it on my own, and I got the D & C.' (Surgical management [S].)

"... and however uncomfortable, or however emotionally, you know, painful it was, I didn't want to speed the process up, I didn't want this unnatural or chemical way, so I, I knew I definitely didn't want a D & C.' (Expectant management [E].)

A minority, however, were strongly in favour of the need for something to be done to help them — to bring the miscarriage to completion as quickly as possible. Some in the medical group also felt positive because they had been assisted to miscarry naturally:

'I remember thinking about the three options, and coming to the conclusion that, at least a D & C was quick ... because at the time I'd been off work for 3 weeks already ... and I just thought: I don't want to wait anymore, particularly as I don't know what's going to happen.' (S.)

'... it happened the next morning [when] I came home ... and it was a sense of relief really, ... it's ended ... the medical treatment, it's just speeding it up ... it's not actually anyone else going in my body ... it's just a little magic tablet ... it's midpoint ... it's a kind treatment ... it's not your baby whipped out of you, which is what a D & C feels like to me.' (Medical management [M].)

A majority of women in all three groups wished to be allowed to miscarry as it was more 'natural' or because of other beliefs; this was mirrored by many women in the surgical group believing that they had been denied a choice in the management of their miscarriage. Some also felt that there was benefit in consciously experiencing the miscarriage, particularly in terms of grieving for their lost baby. This gave them the chance to say goodbye; a few

carried out rites of passage, often devised by themselves:

'... it's very clean, very quick, wonderful operation, but, in a way, I think probably letting it miscarry helps to grieve in a funny way, because you're going through your grief all of the time that you are waiting for it to go, and then it goes, and you do a sort of mental realignment or whatever, you know, you have time to sort of prepare yourself.' (M.)

Again there was a counterbalancing group of women who wished to avoid further conscious experience of the miscarriage and so preferred a D & C (this is the term that women uniformly used to describe the operation of evacuation of retained products of conception — an ERPC — from the uterus):

E: '... but, it was just awful, having to wait, like wait ...'

Researcher: 'And was it on your mind all of the time?'

E: 'A lot of the time, yeah ... yeah, you know, I was walking around, waiting to lose my baby.'

Going beyond the principle of whether intervention was good or bad, there was a nearly uniform fear of intervention, especially of an anaesthetic. Being hospitalised and undergoing operations are seen by many as inherently traumatic events. There was also a strong wish to avoid being 'messed about with' on top of the trauma of the miscarriage. Women particularly viewed the whole medical management process negatively when they eventually still had to have a D & C; in comparison those women who had had no initial intervention, that is, the expectant group, rarely mentioned the need for a subsequent D & C as an issue for them:

'I was more worried about the anaesthetic, that sort of worries me, just sort of being knocked out, and I'm always afraid about not waking up again ...' (S.)

'... yeah ... I really didn't want to have anything done. I thought it was bad enough having lost it, without having to have any more fiddling around.' (S.)

E: 'That was another reason for doing it, because I hate hospitals, I hate injections, and I was working, I just couldn't see how it was all going to fit in.'

Researcher: 'So, you didn't want to have the D and C?'

E: 'No, I didn't!'

Pain and bleeding

Pain was mentioned mainly by those in the expectant and the medical management groups. Most felt it was severe — like labour or contractions, but some experienced it as tolerable, like bad period pains, to be expected with a miscarriage. Indeed, it was striking how variable were the physical experiences reported:

'I don't remember actually, it was more like period pain and I'd get the odd backaches ... I think that I had a hot water bottle, I just needed something warm on my tummy, and if I moved ... then I was fine.' (E.)

'They said it would be like a contraction, but I mean, it wasn't like a contraction at all, really ... it was like very strong period pain ... I likened it to when I first started my periods, when I was sort of 13.' (M.)

'I didn't actually feel I was prepared for what was coming, because, come the Saturday, when I started miscarrying even more, em, I had like contraction pains, which I would say were as bad as childbirth.' (E.)

'I suppose to all intents and purposes, I had gone through labour, although, obviously a different version, but I did feel, my body did feel as though I'd gone through labour, and of course, I had nothing to show for it.' (M.)

Only those in these two groups mentioned bleeding as an issue, and when they did it was usually as 'severe', 'flooding' and 'lots of clots'. A major problem reported was lack of information about the degree of pain and bleeding they might expect to undergo. Indeed, women in all three groups generally felt that they had not known what to expect from the different methods:

'I started a bit of bleeding on the Saturday evening, and then Sunday, it was just ... you know ... sort of gushing, it was horrid and it was definitely, definitely, definitely worse than just a normal period.' (E.)

'... very heavy bleeding, which was manageable because of where I was ... but would have been absolutely impossible, if I'd, kind of, gone to work, or anything like that.' (E.)

"... I mean, looking back on it, I bled for about 40 hours, and had 40 hours of pain and bleeding; but I think that the actual psychological support I had was so much better, that it didn't seem that bad." (M.)

Women's experiences of care received

A small number of women in both the surgical and the medical management groups felt that there was a lack of caring, and that they were simply part of a 'conveyor belt'; for example, perceived coldness of staff and being left too long alone:

- '... you know, nobody came and showed us any care, apart from when they came to take the commode away, but nobody came in to see us.' (M.)
- "... and I hated it! The whole thing was cold! It was so insensitive, it was horrible! I will never forget how insensitive, and cold it felt." (S.)
- '... you felt like you were ... sort of on a conveyor belt and they just whacked this mask over my face, it was almost like, you know: get through, lie down, shut up [laughs] and we can get on with it, because you are slowing down the process ...' (S.)
- "... and they were just icy cold towards us, weren't they? I couldn't believe it really, it was just like when you take your car in for an MOT, they could have been telling us anything ... they didn't show any emotions." (M.)

In contrast, several women in the expectant group commented that although the experience was upsetting for them they found it reassuring to be at home:

- '... so, you know, I thought: no, I'll be at home, I'll be safe, and if there's any real problems, I've got a phone number to ring, or my GP, or we'll just call, if I was really frightened, or worried that it was too heavy ... there is something I can do, and I had some stronger pain killers.' (E.)
- **E:** 'I got home ... lay in bed for 2 days, I was bleeding quite heavily, and I have to say, I'd never go back to a surgical miscarriage, having had an expectant miscarriage, which is a complete reversal to what I expected.'

Researcher: 'That's really interesting, so what kind of changed your mind?'

E: '... it was ... you're at home, you're with

people who care for you ...'

Comments were not frequent, but as patients generally find it hard to complain or pass negative comments on doctors and nurses, they should be considered significant. Those who gave accounts of previous miscarriages they had experienced outside of the trial were often likely to come up with examples of poor quality care or inconsiderate or insensitive treatment from medical or nursing staff.

Finality: the need for an ending

In all three groups there were two themes that related to women's wishes to see an end to the episode. These were that it should come to a predictable end so that they could get on with their normal lives, and also that there should be some predictability to their experience, that is, its symptoms and management.

'I would have preferred to have a D & C, although I'm not sure what that would be like, exactly what that is, but, at least there would be an end to that, like you know: one minute you're pregnant, and the next minute, it's finished and you can get on with your life.' (M.)

'And it was like: I wanted it done, I wanted it done now. I wanted to get home for tea, sort of thing, that was how I was: can't we just do it.' (S.)

- "... after it had happened, I just thought: let's get this sorted, you know, and get back to normal, rather than thinking: oh, what's gonna happen now then, you know, and worrying about it, I thought: let's get the tablets and get it over with, or have an operation and get it over with and then I can go home." (E.)
- '... but we had tickets to go out, and we had the baby sitter organised, and we were having a weekend away on our own, and it meant that we couldn't go, so it was more the inconvenience ... as opposed to actually having to go in, and go through it.' (S.)

They wished not just to know that it would come to an end, but also what to expect in terms of symptoms such as bleeding and pain. They also wanted more accurate and precise details of the timing of interventions:

'If I'd never had a miscarriage, I think the thought of an expectant miscarriage is quite alarming, because you really don't know what to expect at all.' (E.) "... well, I was tired, and I didn't know it would happen did I? I just went for a wee and wiped myself and there it was ... I was shocked, and I just held it, touched it, examined it, and I did feel a bit sick." (M.)

"... and I just thought: I don't want to wait any more, particularly because I don't know what's going to happen, and, oh, the first time I'd read a book about miscarriage, and it, the most awful stories always get in there, I mean I was, you always get those sorts of stories and you think, "oh my God, you know, what on earth is going to happen?" So I just thought: right, I'll go for the most invasive was of doing it [laughs], which at least, gets it over with.' (S.)

'I wanted to. I didn't want to sort of just go home and wait for a miscarriage, erm, ... because I, I didn't know what to expect at all.' (S.)

Medical management

There were some particular experiences commented on by the women who had medical management. Many women expressed concerns about the time the whole process took. There were several components to this: firstly those with a missed miscarriage were given tablets and then sent home for 48 hours; then women with both miscarriage types had to wait for a free bed to be admitted; then they had to wait for the tablets to work. Some also felt that they had been given insufficient briefing about the effects of the tablets and how long it might take them to work.

'I was given one tablet, there and then, on the Friday morning, erm, and told to come back on the Sunday, when they'd do the second part, erm, Friday night and Saturday morning I was severely sick, so, erm, Saturday morning, I had a lot of stomach pain as well. Saturday morning I was taken back in to hospital, erm, where they asked me if I'd agree to continue and I said: yes, as long as they could sort out the pain. So they controlled the pain, they gave me the second part of the treatment, erm, nothing happened on the Saturday, so by Saturday night, they said that I could go home, and come back Monday, when they would see what had happened.' (M.)

Feelings about the 'baby'

Many women expressed views about seeing a 'baby' during their miscarriage. Some were particularly worried and scared about what they might see and what they could do to avoid it, whereas another group felt it was important to see the baby and be allowed to miscarry naturally.

Some women expressed a desire to see the baby so that they could say goodbye to it and thus finish their miscarriage on their own terms:

'... but you know, I just sort of thought: what's that there? You know and, then, sort of waited, and then when you pull the flush, it's like a real goodbye, you know.' (M.)

'... yes, at least if I was home, I suppose ... [sigh], I know it wouldn't have been nice, but I could have said goodbye properly or, I could have been there ... mm ... and it would have been under our control ... I couldn't save this little one [very tearful].' (E.)

'... and now this little one had got so far, and I couldn't protect her either, because, I mean I was able to have [name], but this was different, because I felt that this baby ... I mean, what was left of the baby was being taken away from me.' (E.)

'... and I picked it up, and I was going: Mum, Mum, come and have a look [laughs].' (E.)

A few women wished to avoid intervention as they felt that if there had been a misdiagnosis that they were participating in some way in killing their baby, whereas others were concerned that the baby was dead and they were carrying it and wanted to have the foetus removed as soon as possible:

'I was very relieved that it had miscarried naturally 'cos I could cope with it dying naturally, that wasn't a problem, with the thought of having it killed on purpose, that's how I would have seen it.' (M.)

Some expressed a kind of horror at the thought of carrying something dead inside their bodies:

'I think that that's one of the scariest things: knowing that something inside of you is dead.' (E.)

'... but I remember, when they first told me, I remember I was sort of like sitting on the bed, and I just sort of thought: god, get it out of me! And, it was; that felt really strange you know what I mean, because at that time, they hadn't explained that it wasn't actually growing.' (E.)

DISCUSSION

Summary of main findings and comparison with existing literature

This paper reports for the first time an in-depth and

systematic analysis of women's experiences of all three miscarriage management methods that are used worldwide. Previous qualitative work has not been so extensive or based on such a systematically derived sample. The majority of interviewed women were recruited from the largest ever randomised controlled trial of early miscarriage management, with a minority being non-participants. This trial suggested no difference in gynaecological infection between the three management options, although there were more unplanned admissions and interventions in both the expectant and medical groups.24 The major finding of this qualitative study was the widely divergent views of women in a number of areas. In terms of women's subjective responses to what they had experienced, there is clearly no 'one best way' to treat miscarriage that suits all individuals. This points to the current stress on the importance of people being able to make 'choices', a value now very strongly culturally embedded in consumerist societies, and a choice that may well be different from their professional carers.25-27 Thus, many women strongly expressed their desires for an informed choice among methods. This must include full information on the possible outcomes of each method.

One of the key issues for women was clinical intervention in the physiological process of miscarriage. Most women questioned retrospectively whether such an approach was necessary, this finding being consistent with many other studies of women's views where medical treatment is often seen negatively.¹⁸⁻²² In contrast, a minority welcomed medical intervention, which is likely to enhance their satisfaction with medical care.28 However, whatever their view of the necessity of intervention or not, there was widespread fear of the intervention per se; this included both fears of anaesthesia and some surprisingly strong anxieties about having an operation.21 Both of these specific areas of concern might be allayed to some extent by better information to women and their partners when admitted, and during the miscarriage process. Many authors have found that timely, appropriate, information is often lacking for women suffering miscarriage.29-31

How care is provided by healthcare professionals is crucial to women's experiences;³¹⁻³³ the better the care, the better the expressed satisfaction with that care.³³ In this study some women perceived a lack of caring by some healthcare professionals, as has been found before.^{29-31,34-36} This can be perceived by women as a lack of sensitivity,^{31,35-37} as just being a 'routine' case,^{16,34,38} or as being an object of care rather than being cared about.²⁹ In contrast, many women perceived that they were cared for well by their partner and/or relatives while miscarrying at

home. There was, however, considerable praise for some individual health professionals, especially individual nurses or GPs.

Most women wanted closure or a sense of finality to their suffering, or if this were not possible then at least some predictability in the course of their miscarriage. This can be interpreted as a need for control, and is congruent with their desire for choice, albeit a 'false' choice. For the great majority of women who participated in the trial, their 'choice' was to agree to take part or to have an operation. By choosing the trial perhaps they were electing to take the choice of treatment away from their immediate professional carers, so that they were on an even footing with them as women.

Better information may well have helped those women who specifically mentioned that they experienced either severe bleeding³³ or pain or both. However, prior to the trial only general information of this nature could be provided to women; now the trial has provided the more specific information²⁴ that women desire and put them in a better position to choose which management option they prefer. In particular, the risk of a second intervention must be explained and discussed; we found that women in the medical management group in particular resented having a second procedure (an operation) after they had already received one intervention (drug treatment). In comparison, those in the 'wait and see' group did not experience a subsequent operation for 'failed' treatment in such a negative way.

Strengths and the limitations of the study

The study has some limitations. The group of women interviewed were mainly white and middle class and most had chosen to take part in the miscarriage (MIST) treatment trial and then to be interviewed about their experiences. We should also note the fact that there may have been a 'Hawthorne effect' with women contrasting the concern that was shown them as part of the trial with earlier experiences where they felt the treatment had been more brutal and less caring. In particular, the nurse-recruiters were valued for the information and sympathy they offered the trial participants. Another key issue was that trial participants were offered a much appreciated followup session, giving them the chance to talk about future reproductive issues, which is not normally part of routine NHS care. However, their experiences are consonant with those reported by women in other published qualitative studies. 16,17,30 Our findings would support the assertion that women vary in their expectations, experiences and needs when they miscarry in early pregnancy.

The strengths of this study are that it sought the views of women receiving all three types of

management from both within and without the trial; it used rigorous qualitative methodology; and it triangulated the views of women with those of their recruiting nurses and relevant healthcare professionals. The results therefore are valid and generalisable to UK practice.

Implications for future research and clinical practice

We would strongly suggest that women are provided with accurate, timely, understandable information upon which to make their own decision about the management method they would prefer. For a minority who do not wish to (or who cannot) make such a choice their professional carers will need to do so on their behalf. At least now, using information from this qualitative study and the linked clinical trial²⁴ (Petrou S, Trinder J, Brocklehurst P, Smith LF, unpublished observations, 2005), both women and their carers will be better informed to make such difficult decisions.

Future research could address a number of outstanding issues with respect to miscarriage management. These include: whether providing women with better information prior to intervention (if any) improves from their perspective the quality of the care that they receive; whether hospitals have the capacity to offer various management options; if formal follow-up of women after miscarriage is of benefit; and if given the choice, some women would prefer to avoid medical involvement in this physiological process.

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Ethics committee

Approval was obtained for this study from Bath Local Research Ethics Committee (BA2/99-00); UBHT Research Ethics Committee (E4385); Southmead Medical Research Ethics Committee (034/99)

Competing interests

All authors state that there are none. All persons working on or contributing to this study were independent of the grant awarding body

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