

A qualitative investigation into women's experiences after a miscarriage: implications for the primary healthcare team

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SUMMARY

Background: Approximately 16% of clinically confirmed pregnancies end in miscarriage. However, there is frequently no routine follow-up by the primary healthcare team (PHCT) to identify psychiatric morbidity after miscarriage.

Aim: To explore women's experiences of miscarriage care that may impact on the ability of the PHCT to detect psychiatric morbidity after a miscarriage.

Design of study: Qualitative study using questionnaires, semi-structured interviews of patients, and interviews of healthcare professionals in focus groups.

Setting: Patients who had experienced a miscarriage were recruited from the gynaecology wards of a district general hospital. The healthcare professionals were recruited from 14 local general practices.

Method: Post-miscarriage 'psychiatric cases' were identified using the hospital anxiety and depression (HAD) scale. A theoretical sampling technique was used to identify patients for semi-structured interviews. Interviews with healthcare professionals were conducted in three focus groups.

Results: Seven themes emerged from the interviews and focus groups that characterised the experience of patients and the perception of health professionals after a miscarriage. These were a need and desire for formal follow-up plans, poor recall and understanding of initial events, a need for more information and answers, normalisation of miscarriage by the PHCT, guilt and false assumptions, variable standards of care and skills deficiencies, and suggestions for further improvements.

Conclusion: Themes that emerged from interviews, questionnaires, and focus groups indicate that there are deficiencies and inconsistencies in current care provision that are likely to impact on the ability of the PHCT to identify psychiatric morbidity following a miscarriage.

Keywords: women's health; miscarriage; psychiatric morbidity; qualitative study; guilt.

Introduction

AN estimated 70 000 to 90 000 miscarriages occur in England and Wales annually. Epidemiological studies show that between 11% and 16% of clinically recognised pregnancies end in spontaneous miscarriage, and up to a third of women will have at least one clinical or subclinical early pregnancy loss during their reproductive years.^{1,2}

The emotional consequences of miscarriage have been documented in several studies that describe increased rates of psychiatric morbidity, including depression and anxiety, which persist for several months after miscarriage.³⁻⁵ Despite the recognised psychiatric impact of miscarriage and the reported level of dissatisfaction with professional emotional care,^{6,7} follow-up appointments are not offered routinely after a miscarriage.

It is unclear which factors in a woman's post-miscarriage care determine the ability of the primary healthcare team (PHCT) to identify psychiatric morbidity after a miscarriage. It is therefore important to supplement the existing quantitative data with information on the perception and experiences of care from the perspective both of those who have experienced a miscarriage and of the PHCT. The primary aim of this study was to explore the major factors that could influence the ability of the PHCT to identify psychiatric morbidity in women who have experienced miscarriage.

Method

The study was conducted in north-west Lancashire over a 9-month period during 2000. There were three main stages, namely identifying post-miscarriage 'psychiatric cases' by means of the hospital anxiety and depression (HAD) scale, the collection and analysis of data from questionnaires and semi-structured interviews for both 'psychiatric cases' and 'non-psychiatric cases', and finally interviews with healthcare professionals in focus groups.

Patients

The study sample consisted of 100 consecutive admissions, following miscarriage, to the gynaecology ward of a district general hospital in Lancaster. The inclusion criteria were (a) diagnosis of miscarriage, (b) age over 18 years, and (c) ability to speak English.

Questionnaires

Questionnaires were sent to the women by mail following discharge, both at 1 week and at 8 weeks after miscarriage. A time scale of 8 weeks was chosen to identify probable psychiatric cases because, according to DSM-IV criteria, 8 weeks after a loss is the time threshold after which the

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HOW THIS FITS IN

What do we know?

There is an increased rate of psychiatric morbidity after miscarriage, but commonly there is no routine systematic follow-up of patients by the primary healthcare team to identify psychiatric morbidity.



What does this paper add?

A number of differences have been identified in the attitudes and expectations of patients and health professionals with regard to care provision after miscarriage. The central themes relate to the need for formal follow-up plans, understanding of initial events, requests for more information and the need for appropriate timing, the normalisation of miscarriage, guilt and false assumptions, and the variability of care provision. These factors are likely to have a substantial impact on the ability of the primary healthcare team to identify psychiatric morbidity after miscarriage.

depressed mood of bereavement can be considered to be part of a major depressive disorder.⁸

The week 1 and week 8 questionnaires were identical in content. They contained open-ended questions about the patient's treatment, follow-up plans, feelings and experiences. The questionnaires were also used to collate demographic data, obstetric and medical history, and HAD scores. Non-responders were followed up and sent a reminder questionnaire twice, with a follow-up telephone call if necessary.

Semi-structured interviews

A theoretical sampling technique was used,⁹ in which a small number of similar cases of interest are selected for in-depth interview in order to develop an understanding of the phenomenon under investigation. Subsequently, further cases that might be exceptions are sampled in order to challenge the emerging hypothesis. The sampling stops when no new analytical insights are forthcoming. This procedure yielded a sample of 22 participants who were interviewed. They represented a non-homogenous group with regard to age, gestation, marital status, social status, and 'psychiatric caseness'. The 'psychiatric case' group consisted of patients with a HAD score of ≥ 11 on either the anxiety or depression scale, as previous research has shown this to be highly indicative of a mood disorder.¹⁰

A trained research team consisting of two female health visitors and one male general practitioner conducted the interviews. All interviews were taped and lasted for 45–90 minutes.

A topic guide for the interviews was developed by pilot interviewing using an iterative process whereby issues and topics were developed for later interviews according to responses offered in earlier interviews (Box 1).

In addition to the patient interviews and questionnaires, to complete the final arm of the triangulation of the data, interviews with healthcare professionals (general practitioner [GP] principals and associates, health visitors, practice nurses, midwives, counsellors, and district nurses) took place in three focus groups, each with five to six participants. These discussions were organised in three stages; a résumé of our research aim, a discussion of personal and

- Presentation of the miscarriage
- Nature of problems experienced (physical, psychological, social)
- Past experience of seeking help
- Help sought both formally and informally
- Perceptions of care and support from primary care, secondary care, and the family unit

Box 1. Interview topic guide.

professional views on miscarriage care in the community, and comments on the findings and agreement on the themes that emerged from patient interviews and questionnaire data.

Ethics

The Lancaster, Kendal and South Lakes Research Ethics Committee approved the study. A major ethical issue concerned the psychological distress that might be caused. However, several similar studies have found that the initial and subsequent questionnaires and follow-up interviews may have an unintended therapeutic effect.⁵

Analysis

Qualitative data. A grounded theory-guided approach was employed in this study, whereby only the initial framework of the investigation was predetermined. This allows the research process to be developed in response to ongoing analysis of the data.⁹ The interview transcripts and questionnaire text were coded into meaningful units and, in an iterative process involving constant comparison, these were clustered into data-generated categories. A hierarchy of categories was thus developed, culminating in seven themes that represented the core findings.

Reliability. To increase the reliability of the analysis, a synopsis of the results was later presented to other members of the research team, the codes were discussed, and agreed themes were generated by this inductive approach.

Validity. To increase the validity of the analysis, these themes were summarised and discussed with the patients in the later interviews to determine whether they regarded the findings as a reasonable account of their miscarriage experience. These themes and any diverging views were referred back to the focus groups for discussion. Transcripts of the discussions were analysed by noting points of agreement and, more importantly, any diverging views between the groups.

Results

A total of 100 patients volunteered to participate in the study, and 71 GPs (representing 30 practices from the local area) were responsible for the general medical care of the patients.

There were 82 completed sets of questionnaire data. Seven women dropped out of the study after the initial recruitment and did not respond to either follow-up letters or telephone calls. Eleven women dropped out after completion of the first set of questionnaires (week 1 questionnaires). These 11 women did not differ significantly in terms of marital status, social class, gestation, number of living children, previous history of miscarriage, or HAD depression score from the

participants with completed questionnaire data. Among the participants with completed data, 28 (34%) women were identified as probable psychiatric cases. The average age of the participants was 31 years (range 16–44 years), and 74% were social class I–III (i.e. in non-manual occupations). Other descriptive data are shown in Table 1.

Single females may have an increased probability of a psychiatric illness following a miscarriage. Table 1 shows that the only characteristic that distinguished the psychiatric and the non-psychiatric caseness groups was marital status.

Seven themes emerged from the analysis of the data generated from the interviews, qualitative questionnaires, and focus groups (Box 2). Quotations are taken from the transcripts of interviews and from the free text from open-ended questions in the questionnaires.

Theme 1: Need and desire for formal follow-up plans

On discharge from hospital for various illnesses, patients are placed in a position of autonomy over their future medical care as appropriate for their condition. The medical professionals often leave it up to the patient to seek further consultation and medical attention if it is required or if a new problem develops. However, the women in this study frequently regarded this approach as inadequate, and considered formal follow-up plans following discharge from hospital to be a high priority:

'They wouldn't dream of taking somebody's appendix out and saying "bye, we won't see you again", you have the follow-up appointment to make sure everything is OK, but for some reason with miscarriage it isn't.' (O49-9.)

'I think the real blow comes a few weeks after the actual miscarriage. There needs to be some kind of aftercare either from the GP or the hospital, especially regarding ways to deal with the depression or lack of interest in sex following miscarriage. Nobody seems to care afterwards.' (B085-1.)

A GP was perceived as being well placed to provide follow-up if required:

'My GP was aware that the miscarriage was not particularly upsetting for me as I was considering a termination, and he offered his advice and support when I have needed it but hasn't gone overboard. He has acted in a sensitive and understanding way.' (B063-2.)

The PHCT focus groups broadly agreed that patient dissatisfaction was exacerbated by the absence of formal follow-up plans, and that physical, psychiatric and social needs were not being addressed:

'I really do think there is a need, which perhaps could range from simply the service acknowledging that this sad event has occurred to offering a more sort of long/medium-term support, I think the vast majority of patients need something.' (Health Visitor LR.)

Theme 2: Poor understanding of initial events

Women commonly experienced confusion and inability to absorb information during their hospital stay:

'At the time I was so devastated I just wanted to go home, but over the week there are loads of questions in my head that I need to know the answers to.' (A008-2.)

'I was confused, I didn't know what was going on. I never read them [miscarriage leaflets], 'cause I was too upset, you see.' (O44-6.)

The timing and value of providing inpatient information for miscarriage patients were undermined, as patients did not always retain this knowledge for future use:

'... the hospital nurse talked to me too early. I rejected her advice as it hurt too much. I was not ready to talk to anyone.' (B061-1.)

The timing of doctor–patient communication and interaction had an important influence on patient perceptions of management and care:

'I saw the consultant about an hour after I came out of surgery and I wasn't compos mentis. I mean don't get me wrong, he was a lovely man, but you would be better seeing somebody 6 weeks down the line, you might be emotionally better to talk about something like that.' (O49.)

Theme 3: Need for more information and specific answers

Women wanted more information and specific answers regarding the possible implications of the miscarriage, despite the availability of written and verbal information at discharge:

Table 1. Characteristics of women with and without a probable psychiatric illness at 8 weeks following a miscarriage.

	Non-psychiatric caseness (n = 54)	Psychiatric caseness (n = 28)	Interviewed women (n = 22) ^a
Single	12	16	8
Childless	25	13	5
Past psychiatric history	3	5	1
Previous miscarriage	8	9	7
Unplanned pregnancy	17	12	2
Average number of weeks pregnant	10	10	11

^a10 of 22 of these women had psychiatric caseness at week 8.

- Need and desire for formal follow-up plans
- Poor understanding of initial events
- Need for more information and answers
- Normalisation of miscarriage by the primary healthcare team
- Guilt and false assumptions
- Variability of care/skills deficiencies
- Suggestions for further improvements

Box 2. Emergent themes from analysis.

'I wanted answers which nobody could give me. The answers that I wanted. I mean even to this day, that's all I want is answers.' (O49.)

This lack of answers may account for the high levels of reported anxiety symptoms:

'I wish someone had given me an explanation, as it would have helped me come to terms with it better. I need the real reason, not "it's one of those things".' (O49.)

'I feel angry and confused, as I was not really told why I had lost the baby.' (A100-1.)

Some women were more prepared to accept that simple answers were not always available:

'I still don't know the explanation, although I accept it isn't always possible to know the cause and it is a common occurrence.' (B076-2.)

Theme 4: Normalisation of miscarriage by the health profession

Many women perceived a lack of compassion from the PHCT towards their miscarriage:

'I also found that the doctor at the hospital spoke about losing the baby as "it happens all the time", so too did the midwife, lacking feeling and empathy.' (A029-2.)

The fact that miscarriages are a frequently encountered medical problem may influence patterns of communication and impede the ability of professionals to empathise with individuals:

'...the nurse in the hospital says there is no reason, it's just life.' (B073.)

'You've got all these people at the hospital doing this and doing that but they don't understand how you're feeling, they are just doing their job, aren't they?' (O44-9.)

Accounts offered by the PHCT focus groups recognised the signals that portray miscarriage as an unremarkable life event, and highlighted the normalisation of miscarriage as the predominant strategy of many health professionals when managing miscarriage. Explanations based on statistical frequencies combined with the absence of follow-up plans are interpreted by many women as health professionals lacking empathy.

'The big thing that they find difficult to accept is when the professional tells them this is a very common thing. For

them it's only happened this once or perhaps a few times, but to them it's a devastating, major, life-changing, life-shattering event. So to be given the kind of information that is supposed to be helpful, "well this happens a lot", "one in five" or whatever the statistic is, is not helpful to women. They don't want to hear that.' (Health Visitor LR.)

Health professionals also appreciated that 'normalising' events may be inappropriate for some patients:

'Maybe some doctors as well as being blasé, maybe they are trying to normalise the experience and trying to reduce its impact. That it is quite normal to have a miscarriage.' (Practice Nurse AE.)

'Yeah, that it is and there's nothing wrong and it will get better, but by doing that they are not actually looking at how devastated the woman is.' (General Practitioner NG.)

One outcome of the normalisation process is the consensus view that simple strategies to aid recovery following a miscarriage are open to the individual:

'It's just forgotten about and they are supposed to forget about it, but they don't.' (Health Visitor LR.)

'...and that's often reinforced by friends, family and even employers, "You know you just get on with it, these things happen and it's common".' (Counsellor AE.)

On the other hand, some women found that the medical terminology could protect them from certain aspects of the painful experience of miscarriage:

'Personally I have found it easier to deal and cope with my miscarriage by not referring to it as a loss of a baby, but by calling it by medical terms. Referring to the loss of a baby may be upsetting for some women.' (A-065-1.)

Theme 5: Guilt and false assumptions

Feelings of guilt following miscarriage were frequently expressed, and may have a negative impact in terms of emotional health as well as presenting a psychological barrier to help-seeking behaviour. For many women their guilt was compounded by a deep sense of failure owing to the feeling that they were letting people down:

'There is a huge amount of guilt, particularly immediately following a miscarriage. Firstly regarding how have I contributed to the miscarriage by doing or not doing something, but secondly in having let everyone down.' (B097-1.)

Women appeared to experience guilt for several reasons. Many of them felt guilt about not conforming to the assumptions made by friends and relatives. Ironically, a common false assumption was that all women experience a miscarriage as a traumatic and life-changing experience:

'I realise most women would be upset and need to be carefully treated, but I was made to feel guilty that I was

not upset or grieving.' (A063-1.)

On the basis of either second-hand knowledge or previous personal experience, some women adopted an over-generalising and dismissive approach. The health profession was seen at best as being moderately indifferent to miscarriage, with a uniform professional attitude that normalises the experience. Consequently, women were unprepared for any exceptions to their view and failed to seek medical attention and advice:

'I didn't go to my doctor, because if you're not actually going with a problem I always feel guilty, I think doctors are not there to have a social chat, they are very very busy people, they haven't really got the time to sit there and discuss something like that.' (049-13.)

Theme 6: Variability of care and skills deficiency

Women gave a very mixed set of responses to the attitudes of and quality of advice and support offered by health professionals, friends, and family. Accounts ranged from a high level of satisfaction to feelings of disgust with the level of support received:

'I was lucky to have a knowledgeable friend [a health visitor] who knew not only the medical knowledge but also the personal. Otherwise support was poor.' (A019-1.)

'My GP gave me an explanation as to why this could be happening. My GP has been very understanding and a great help when needed.' (A035-1.)

The variability in the quality of aftercare suggests that there is a high degree of inconsistency in the way in which the physical and emotional needs of these patients are addressed after discharge from hospital.

The focus groups regarded skills deficiencies as a prime factor contributing to the lack of consistency in information and care across all health professions:

'Health visitors sometimes feel that they have not got the skills, they might go for a follow-up visit, but don't feel able to cope with what they might encounter.' (Health Visitor LR.)

"Why did it happen?", "What are the possible causes?" I know certainly in the past when I was newly qualified, I felt completely unprepared for these sorts of issues.' (Health Visitor ER.)

Theme 7: Suggestions for further improvements

Both the focus groups and the patients had suggestions for improvements to the current community care that is provided for women after miscarriage. The main areas were as follows.

First, it was important to identify the health visitor as the key carer/lead in post-miscarriage care:

'I've already got a good relationship with my health visitor, so her coming and knowing my problems would have been perhaps the best way for me. She was coming to see my other little children anyway.' (District Nurse who had miscarried DN.)

The health visitor is likely to have an established relationship with the woman and her family, unless the woman is a primip or there have been staff changes among health visitors, which can frequently happen. The intervention from a health visitor is thus unlikely to be regarded as an intrusion and patients may be more open to discussion and advice.

Secondly, the need to establish a formal follow-up procedure has emerged as a central theme from this study. The implementation of formal follow-up plans and the notification of the lead carer may prevent cases being missed:

'...as health visitors we've raised concerns at times in the past that we just haven't been notified.' (Health Visitor LR.)

The groups explored the various options available, and the consensus was that a fail-safe system was preferred:

'I think the formality makes it more efficient to make sure it gets done. I think if you formalise everything as well it helps reassure people that it is a significant event.' (General Practitioner ML.)

It is suggested that key carers, like health visitors, should be formally notified of individuals who have miscarriages. One model that was agreed on includes a post-miscarriage check at 6–8 weeks by the health visitor to help to identify psychological and psychiatric morbidity. At that time, women would also have the opportunity to discuss any fears or concerns that had emerged:

'I think, like postnatal depression, we should be looking for it in everybody who's had a miscarriage.' (General Practitioner ML.)

Thirdly, addressing educational needs was identified by the PHCT as a means of equipping key carers with the skills and experience necessary to manage the emotional impact of miscarriage:

'Providing people in primary care with more, not basic counselling skills because you've got them haven't you, but maybe specific skills that relate to things like bereavement and miscarriage so that you at least don't say the wrong thing.' (Counsellor AE.)

Healthcare workers were acutely aware of their own lack of experience and vulnerability when dealing with miscarriages:

'I think perhaps maybe we shy away for fear of upsetting mothers even more, or there may be a perception that the mothers may be upset.' (Health Visitor ER.)

Being equipped with the appropriate skills and miscarriage experience was regarded as an important way of helping carers to manage miscarriage issues:

'I think sometimes all you need is reminders, people who are having miscarriages do need a gentle approach instead of being blasé. I don't know, I think sometimes

you just forget.' (Community Midwife CM.)

Education of key carers in the community was also seen as a way of ensuring a higher level of consistency in the provision of information and management plans:

'We don't generally go on study days about how to manage miscarriage, we all think we're probably being compassionate towards people, but do we really have up-to-date information? Do we really know what the services are? Do we know what everyone else is saying?' (Health Visitor ER.)

Discussion

There is an evident gap in service provision for miscarriage care as perceived by many women who have experienced a miscarriage and also by some health professionals.

A key factor in the current dissatisfaction with service provision appears to be a lack of effective communication. This communication failure may adversely impact on the ability of the PHCT to detect post-miscarriage morbidity, and it compounds the distress of patients. An attitude that inadvertently normalises the personal experience of miscarriage presents a barrier that results in the needs and difficulties of patients frequently being missed. Such an attitude may also alter an individual's help-seeking behaviour, presenting a further obstacle to the detection or prevention of psychiatric morbidity. Over-generalisations pose yet another barrier to effective communication between healthcare professionals and the patient.

There are further disparities between the patient's needs and current practices within the health profession in managing a miscarriage. In particular, the lack of routine follow-up plans was regarded as an area of high priority by many patients. Current provision of patient information and explanations before discharge from hospital appears to be either inadequate or inappropriately timed. The lack of routine follow-up may result in anxiety and dissatisfaction with the healthcare profession, and may represent a lost opportunity for healthcare professionals to detect physical and psychological morbidity after miscarriage. There appears to be wide variation in the quality of provision and patient support within the health service after miscarriage. A deficiency in training in skills that are specific to miscarriage care was identified by the health professionals as a possible source of this variation.

Strengths of this study and relationship to the existing literature

The HAD data were collected in this study to identify women with a probable psychiatric illness, thus allowing the purposive sampling of both probable psychiatric cases and non-cases for interviews. This data also enabled us to ensure that our study population was consistent with those of previous miscarriage studies in that it shows a two- to four-fold increase in the rate of psychiatric morbidity 8 weeks after miscarriage in the general population.^{4,5,11} In the present study, being single was the only factor that was predictive of psychiatric illness.

This study supports the findings of Prettyman and Cordle,¹¹ who reported that health professionals are aware that miscarriage is frequently associated with significant psychological distress, and that there is a gap between perceived need for and provision of care for women who have

had a miscarriage. Our study findings are also consistent with those of Friedman,¹² who showed that women were both dissatisfied with the information they received and felt there were differences between themselves and their GP with regard to the perceived seriousness of the impact of miscarriage.

Limitations

This study only recruited women who were admitted to hospital with a diagnosis of miscarriage, thereby excluding those who had not been referred for secondary care. This exclusion was designed to avoid inconsistencies in miscarriage records in primary care.¹³ Many patients may also fail to present to the PHCT, or only present several weeks after the miscarriage, making it difficult to obtain data within 1 week of the miscarriage.

The study was also limited to native English speakers, owing to the language skills of the research team and the qualitative design of the study, which used English-based interviews and questionnaires.

Implications for future research or clinical practice

This study has used a qualitative approach to explore the complex factors that surround the provision of care following miscarriage. The findings reveal a significant discrepancy between patients' perceived needs and service provision. Seven themes have emerged that should yield a broader perspective on women's experiences of care following a miscarriage. This could form the basis for future interventional studies.

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