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An exploration of how women in the UK perceive the provision of care received in an early pregnancy assessment unit: an interpretive phenomenological analysis

Wendy Norton, Lynn Furber

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Leicester School Nursing & Midwifery, Faculty of Health and Life Sciences, De Montfort University, Leicester, UK

Correspondence to
Dr Wendy Norton;
WNorton@dmu.ac.uk

ABSTRACT

Objective The objective of the study was to explore how women experience care within an early pregnancy assessment unit (EPAU) and how they are helped to understand, reconcile and make sense of their loss and make informed decisions about how their care will be managed following a first trimester miscarriage.

Design This was a single centre, prospective qualitative study. An interpretive phenomenological analysis approach was used to interpret the participants' meanings of their experiences. It is an ideographic approach that focuses in depth on a small set of cases to explore how individuals make sense of a similar experience.

Setting An EPAU in a large teaching hospital in the Midlands that provides care to women in their early pregnancy, including those experiencing pregnancy loss.

Participants A purposive sample of 10 women were recruited to this study. All of the women were either miscarrying at the time of this study or had miscarried within the previous few weeks.

Results Six superordinate themes in relation to women's experiences of miscarriage were identified: (1) the waiting game, (2) searching for information, (3) management of miscarriage: no real choice, (4) the EPAU environment, (5) communication: some room for improvement and (6) moving on.

Conclusions This study found that improvements are required to ensure women and their partners receive a streamlined, informative, supportive and continuous package of care from the point they first see their general practitioner or midwife for support to being discharged from the EPAU. The provision of individualised care, respect for women's opinions and appropriate clinical information is imperative to those experiencing miscarriage to help them gain a degree of agency within an unfamiliar situation and one in which they feel is out of their control.

Strengths and limitations of this study

- Using a qualitative approach, this study raises some important implications for the management of care for women and their partners from the point of seeking initial help from their midwife or general practitioner through to the provision of care in the early pregnancy assessment unit (EPAU).
- This study was undertaken in a single National Health Service hospital and may not be representative of other EPAUs.
- The research focused solely on obtaining the women's point of view through interviews but it would be beneficial to also interview their spouses and healthcare professionals, enabling a comparison of a combination of perspectives.

INTRODUCTION

Miscarriage is defined as the spontaneous loss of pregnancy before the fetus has reached viability and can occur anytime within the first 24 weeks of gestation.[1] However, most miscarriages occur in the first trimester and cannot be prevented from happening.[2] It is estimated that between 15% and 20% of clinical miscarriages end spontaneously, but total reproductive loss is considered to be between 50%[1] and 80%[3] with between 25% and 50% of all women experiencing one or more sporadic miscarriage.[4] Clinical miscarriage is therefore common and in recent years research has focused on determining the possible causes of clinical miscarriage and its prevention and treatment, yet there is still much to learn.[5 6]

Evidence links a number of risk factors to miscarriage but it is commonly accepted that a woman's risk increases with advanced maternal age (>35 years).[5–8] More women are, however, delaying starting a family[8] and often underestimate how common miscarriage is[9 10] and underestimate their risk of miscarriage.[11] As a consequence, they are often unprepared when a miscarriage occurs.[12] Several qualitative studies have indicated a need for an improvement in information to help couples

understand the potential risks of miscarriage[10–13] and provide them with information about support mechanisms available should they become concerned about their pregnancy.[10–13]

Over 20 years ago, early pregnancy assessment units (EPAUs) were introduced in the UK to provide a dedicated and centralised outpatient service to streamline and improve the quality and management of care for women experiencing complications with their pregnancy,[14 15] including bleeding and/or pain and a loss of pregnancy-related symptoms.[13 16–18] There are now over 200 of these units in the UK attached to National Health Service (NHS) hospitals according to the Association of Early Pregnancy Units and this model of care is now being replicated in a number of countries.[19 20] Reported benefits for this service from a medical perspective include the timely provision of care, cost savings[19] and a reduction in hospital admissions.[20]

Although there are clear indications that EPAUs have a positive effect on the quality of care for women experiencing complications with their pregnancy,[19] there is still room for improvement.[3 10 17] A lack of sensitivity and empathy,[21 22] poor communication[10] and fragmented care[23] are frequently reported in the literature by women about the care they receive. This is a significant issue. Clinical miscarriage is an unwelcome event and can be an extremely painful and distressing experience, which can negatively impact on a couple's psychological well-being,[10 13 17 18] both in the short and long term.[24] Whereas, women who do receive support and follow-up care by professionals following their miscarriage can result in positive, lasting effects.[13 17]

The current study builds on these findings to explore how women experience care within an EPAU and how they are helped to understand, reconcile and make sense of their loss and make informed decisions about how their care will be managed.[25] Through a qualitative analysis, a key objective of this study was to explore how women's experience and satisfaction with their care, when experiencing a first trimester miscarriage, could be enhanced.

METHODS

An interpretative phenomenological analysis (IPA) approach was used in this study. IPA examines in detail the complexity of how individuals make sense, through reflection, of a particular experience in their lives.[26] Researchers who engage in IPA analyse and interpret the data using a case-by-case approach before looking across cases for similarities and differences in people's reflections of a similar experience.[26] IPA is frequently employed in healthcare research to explore the impact of care on patient experiences.[10 27]

The study took place in an EPAU in a large teaching hospital in the East Midlands, which provides care to a diverse ethnic population experiencing complications with their pregnancy. The EPAU is a nurse-led unit, supported by the gynaecology medical team and a team of sonographers. A purposive approach to patient selection was employed and participants were eligible for the study if they were over 18 years of age, were experiencing a miscarriage within the first 12 weeks of pregnancy, had not experienced a previous miscarriage and were willing to participate in the study. Following the initial EPAU consultation, the nursing team provided women with information about the study and the study team, and details of how to contact the researchers (LF and WN) if they were willing to participate in the study. Both researchers have a nursing background and appropriate experience to work with this patient group.

The researchers aimed to recruit 10 participants who had not experienced a miscarriage before to capture their unique experiences of care within an EPAU and how they were helped to understand, reconcile and make sense of their loss.

The women were aged between 21 and 44 years, were all in a relationship and eight were White European and two were South Asian. Each of the women had visited the EPAU at least once and were in different stages of the miscarriage process. Some had miscarried and some were awaiting final scan results to confirm the loss of their pregnancy. Interviews were conducted within a couple of weeks after the miscarriage or up to 6 weeks later in some cases where a diagnostic decision on ultrasonography had delayed the confirmation of miscarriage.

The aim was to focus in depth on a small set of cases to explore how individuals make sense of a similar experience. Once this number was reached, the recruitment process was stopped. In total, the nursing team handed out 30 patient information sheets. No one withdrew from the study.

All the participants signed an informed consent form and were interviewed individually by LF or WN, using a semistructured interview schedule (table 1). All interviews were conducted face to face and digitally recorded. All of the interviews were conducted in a location selected by the participant. This was mostly in participant's homes, with the exception of one interview, which was conducted on university premises at the participant's request. Contemporaneous notes were taken immediately after each interview recording any further data, which, for example, arose after the interview, when recording had ceased. Interviews lasted between 60 and 90 min in length.

The transcribed interviews were analysed and subjected to detailed analysis by LF and WN. To balance views and strengthen the trustworthiness of interpretations, the researchers read and re-read the transcripts to familiarise themselves with participants' accounts. Each researcher made detailed notes in the margins of transcripts to document exploratory coding and emergent themes and then compared their notes with each other prior to coming to a consensus of opinion. Additionally, each transcript was analysed individually before looking across participants to identify divergence or convergence of themes. This approach helped the researchers move towards a more interpretive understanding of the data. Themes

Table 1 Overview of the questions and prompts used in the semistructured interview

Area of interest	Example questions
Referral process	Tell me who you turned to for help when you were concerned something was wrong with your pregnancy?
	How were you cared for at this time?
	What advice were you given at this stage?
	How did you end up in the EPAU?
Diagnosis	Can you tell me what happened when you miscarried?
	Can you describe how you felt at this time?
Experience in the EPAU	How would you describe the care you received in the EPAU?
	How did the staff communicate information to you?
	What emotional support did you receive at this time?
	Did you seek support from family and friends?
Decisions about management of care	What options were you given about the management of your care?
	How well did you understand your treatment options?
	How did you come to a decision about the management of your care?
Knowledge and understanding	Did you seek information about miscarriage? Where from? Was the information suitable for your needs?
	Did you have any knowledge of miscarriage?
Follow-up care	What support did you receive when leaving the EPAU?
	Did you think you could contact them for further advice?
	Were you informed about counselling services? Did you seek any additional help?
	What might have improved your overall experience of care?

were clustered together and subordinate and superordinate themes were identified. All analysis was integrated into Nvivo V.10 software (QSR International) by LF and a master table of themes was created and presented to WN for final approval.

Patient and public involvement

Women were not directly involved in the design of this study, but the views of women who had experienced a miscarriage were taken into consideration. Women who did participate in the study were asked their views about this kind of research and what they thought about the recruitment process and whether they would want to adapt it at all. The findings of this study will be disseminated to patients via the hospital patient and public involvement communications process.

FINDINGS

Although the primary aim of this study was to explore how women perceive the provision of care and emotional support they receive in an EPAU, following a first trimester miscarriage it became clear that the level of support available before and after their attendance at the EPAU was also significant. Also, while the focus of care was on the woman's experience, some participants described how the miscarriage impacted on their partner who attended most of their EPAU appointments. When the transcripts were analysed collectively, six subordinate themes emerged, but still allowed for some divergence between cases. The themes are the following: the waiting game; searching for information, management of miscarriage: no real choice, the EPAU environment, communication: some room for improvement and follow-up care. Names of women have been replaced with pseudonyms when presenting the data.

The waiting game

Waiting and dealing with uncertainty was considered to be one of the most distressing aspects of the miscarriage experience. There were three key stages where women found themselves waiting: (1) waiting for an appointment to attend the EPAU, (2) waiting for scan results to confirm the miscarriage and (3) waiting for the miscarriage to occur through natural management, medical management or surgical intervention. It was common for women to feel a whole range of complex and often distressing emotions during each of these stages but it was the first two stages that women reported in more detail. Waiting and dealing with uncertainty was considered to be one of the most distressing aspects of the miscarriage experience.

Eight of the 10 participants had started to bleed during their pregnancy and approached their general practitioner (GP) or midwife for advice and support in the first instance. Two women had arranged for a private scan and were told that there were concerns about the viability

Box 1 The waiting game

- "I was surprised because when I spoke to the midwife she said oh they will probably get you in for a scan, it's likely to be Monday or Tuesday, it isn't going to happen over the weekend. So, when it was Wednesday it was a bit, 'oh god, I have to wait four days now to find out what is going on." (Sue)
- "I spoke to my GP and my midwife and was referred to the EPAU. I had to wait four days before I had the appointment there, which I understand but that was really difficult." (Amy)
- "I felt like those three days in between gave me enough time to say goodbye properly." (Elaine)
- "Awful, horrendous, I was a mess for a week. I got that legally they have to wait in case there is any change but in my case I thought it was really obvious that the baby had stopped growing at 6 weeks. It was 4 weeks later, there wasn't going to be a change and I found that really difficult." (Sally)
- "It was the waiting that hurt me the most." (Penny)
- "What has annoyed me is that I looked up stuff when I got home … to figure out what the hell 26 mm is. They kept going on about the fact that it's one mm over da da da da da. We were thinking maybe it's better because that means the baby is bigger but it wasn't the baby it was the sac that was bigger. There was no baby. I only know that because I looked it up. If I hadn't looked it up I wouldn't understand what the hell was going on; didn't have a clue. That was not a good experience." (Claire)

Box 2 Searching for information

- "He was fine [GP] but again not forthcoming with information. I expected him to say now if the pain gets worse or you start getting a temperature or you feel dizzy or sick go straight to A&E. He didn't give me any of those warnings." (Amy)
- "And she was brilliant [Midwife] because she could tell me more about what would probably happen but couldn't confirm anything. She had had 3 miscarriages, which was hugely important information to me because the main thing was I didn't know what to expect. And then of course having read about it more I realised I could have a miscarriage at any point." (Jayne)
- "I have read so many things about it … I read lots of comments of women who have gone through it and just to get myself ready for what was to come. I just felt it was going to be easier if I knew what was going to happen." (Elaine)
- "There's one whole thread, which is just like tips for preparing for a miscarriage. Those women say buy co-codamol, get a hot water bottle. You don't know that stuff. So right I am going to war and I need co-codamol and a hot water bottle; go get me those things." (Jayne)
- "There is no definitive answer and you think well that's just brilliant. I looked online at people's experiences and they were saying 'oh I bled heavily for 2 weeks and then it stopped' and then you read somebody else say 'I bled straight into my next period; 6 weeks bleeding' and you are thinking actually that is more helpful to me at the minute rather than people turning around and saying there is no definitive answer." (Sue)

of the pregnancy. One of these women was referred to her local accident and emergency unit and the other was referred directly to the EPAU.

All participants were referred to the EPAU with the knowledge that they may be experiencing a miscarriage but had hoped that their pregnancy was still viable. There seemed to be an understanding that it could be normal to have some blood loss during pregnancy, which was endorsed by some GPs, midwives or, for one participant, a friend who had experienced blood loss during their pregnancy.

The EPAU in this study predominantly operated on a Monday to Friday, 09:00–17:00 service. While most women received an appointment within a couple of days, three women had to wait 4 days for an appointment. This was a particularly difficult time for each of these women because they were anxious about the viability of their pregnancy and wanted to know what was happening. However, on reflection, Elaine did think that this time gave her the opportunity to say goodbye to her baby (box 1), although her miscarriage had not been confirmed at this stage.

Without exception, each of the women spoke of their urgency to have a scan as soon as possible. However, they were unaware of the limitations of ultrasound in making a diagnosis, and the potential for further scans, over the course of up to 6 weeks in some cases, to confirm a definitive diagnosis. Jayne and Claire in particular had to wait up to 6 weeks for their miscarriages to be confirmed because the ultrasound criteria dictated that the gestational sac needed to be of a certain size before the miscarriage could be confirmed. This was a particularly distressing time for these two women who became fixated on the size of their gestational sac, without really understanding the significance to their situation.

After the initial scan in the EPAU when further doubt was raised about the viability of their pregnancy, women stopped talking about hope for a successful outcome and reported a need to have their miscarriage confirmed so that as Jayne and Claire described, they could stop living in limbo; Penny and Sally could stop feeling like emotional wrecks and Natalie could stop time dragging on.

Searching for information

While waiting to attend their first EPAU appointment, most women spoke of either their partners or themselves searching the internet for information. There was an overwhelming sense that women had no idea what to expect if they miscarried or what would happen to them at the EPAU (box 2). GPs in particular were criticised for not giving women any information about the EPAU service, or information to help them prepare for a miscarriage should it occur before they were seen in the EPAU.

Only Jayne spoke of having any understanding about what might happen to her when she miscarried because her midwife had been very candid and open about her personal experience of miscarriage. Other accounts were more complex as the need for information changed according to the stage of the diagnostic process. Prior to the first scan, some women reported searching for information to reassure them that the problems they were experiencing were a normal occurrence in early

pregnancy. Later, when they were warned that their pregnancy might not be viable, a primary need for information focused on what symptoms they might experience if they had a natural miscarriage at home and how they could prepare for this situation.

Some women described how the EPAU nurses appeared to be deliberately vague about how the miscarriage may unfold due to the difficulty in predicting individual women's experiences. However, women reported needing a stronger indication of what to expect and what to do, having never experienced a miscarriage before. Claire and Sue were particularly grateful for their nurses using very basic terminology to help them understand what symptoms were normal and what symptoms would require medical attention. In contrast, Jayne and Sue searched the internet to find women's real accounts of miscarriage to help forewarn them, as their nurses had not been perceived to be forthcoming with information. When asked which websites they used, participants could rarely remember having looked at so many. Only one woman and her husband looked at the Miscarriage Association website, while others searched various websites and forums for information, despite the EPAU nurses only recommending reputable, NHS websites.

Management of miscarriage: no real choice

When a miscarriage was finally confirmed by ultrasound, the EPAU nurses presented women with written and verbal information about how their miscarriage could be managed. Scan results confirmed spontaneous miscarriage for two of the women and no further intervention was needed. The three management options comprising, natural, medical and surgical intervention were explained to the remaining eight women. Although the three options were discussed in detail, six women did not feel as though they had any real choice about how their miscarriage would be managed. Either the EPAU nurses (five cases) or husband (one case) influenced women's decisions.

In the six cases, where women did not feel that the choice was their own, five of these women described wanting surgical intervention as they did not want to go through the pain of a natural or medical approach and furthermore wanted some control about when the miscarriage would occur. One woman (Kerry) felt that she had not received sufficient information at that time to make a decision and proceeded to have a spontaneous miscarriage, so options were no longer relevant to her case. Three out of the five women who preferred surgical intervention felt that the nursing team denied them this option and they reluctantly complied with the decision to have a medically managed miscarriage without challenging the nurse. However, the women felt that it was not clear why surgery was not an option for them (box 3). In contrast, one woman (Sally) who was told she could not have surgery challenged this decision and insisted on speaking to the doctor after being encouraged to do so by the sonographer; subsequently, the doctor facilitated the surgery at her request. In addition, Natalie's husband felt strongly that a natural miscarriage was the right decision for them as a couple and Natalie complied with this decision.

Box 3 Management of miscarriage: no real choice

- "No they didn't give me an option. It wasn't like they gave me an option. It was more like they [nurses] were deciding what to do. Maybe if I am more confident I will order what I want but I didn't." (Kerry)
- "… I just wanted everything out. I was really angry and I was very upset and I said I will have surgery, give it to me now. And my husband was with me and he said no, you are not in the right state of mind." (Natalie)
- "When she did talk us through our options she said that surgical management wasn't an option and that it would have to be medical." (Jayne)
- "So she went through everything with me and she said the options were pessaries because I was early and it was too small they couldn't give me a D&C. So there was my option out the window. That is what I wanted. I was a wreck" (Penny)
- "I would like to have been able to have the control of making my own decision … I felt I had no control over it." (Sally)
- "She was saying well [nurse] we could wait two weeks but after two weeks we would want to get involved and do the medical management … but I was happy to do it naturally. I would rather not take any drugs." (Claire)

The EPAU environment

On arrival at the EPAU, women sat in a waiting area until they were called to see the EPAU nurse who collected some clinical data and then arranged for an EPAU sonographer to perform a scan.

Women's accounts suggested that there was often a lack of understanding and explanation of what was going to occur during their time in the EPAU. In addition, women were often unaware that they were consulting with a nurse and three women thought the nurse might have been a midwife or a doctor. In addition, during ultrasound scans there were other people present in the ultrasound room that women were not introduced to. Three women described how the ultrasound room was used jointly as a patient scanning area and a computer workspace for other sonographers; a movable screen divided the room. Natalie, Amy and Jayne were particularly concerned about this arrangement and felt that it impacted negatively on their level of privacy (box 4). Additionally, it was not uncommon to have a second sonographer in the main scanning room taking notes and/or for a student (unknown speciality) to be present. Natalie in particular did not want these people present in the room but felt that she was not given the opportunity to ask them to leave.

Following the scan, women and their partners would either return to the waiting room or were taken directly into a consulting room to wait for the nurse to see them. Some women felt very anxious about crying or getting upset in front of other women in the waiting room because they did not want to distress others. However, in contrast

Box 4 The EPAU (early pregnancy assessment unit) environment

- "I don't know if she was a nurse helping out or a sonographer." (Sue)
- "Behind the screen were computers and other sonographers working whilst you were being scanned on this side of the screen. I thought it was weird. I thought any minute I am going to have to get undressed … I thought it would have been much better if those people behind the screen were working in another room. If you were having a moment, if you were really upset or this was completely shocking news for you … it's not appropriate." (Amy)
- "Whilst I was being scanned there was a curtain and a lady there who went to the computer. The sonographer realised I wasn't expecting anyone to come in and she said 'oh don't worry that's just my colleague'. I think I would have preferred privacy in that room. The other thing was the student. I would have preferred not to have the student there." (Natalie).
- "… people were going for the scan and then coming back into the room and were happy, and you just knew that wasn't going to be you. If that had been me on Tuesday I wouldn't have been able to sit in that room … I was in a state all day and it's not nice for other people, some woman sitting sobbing in the corner. It's just grim." (Amy)
- "The one time they didn't put me in the quiet room I asked to be put there because I was crying." (Claire)

Box 5 Communication: some room for improvement

- "I could say anything. With care they talk. When you are asking questions they answer, they have time, they don't rush. I don't feel ignored. I could say what I like. You can feel people bless you, so you're not nothing. It wasn't like the thousandth of the day. You feel like everyone is different. I feel they care." (Kerry)
- "He felt ignored. It was as though he wasn't there. It was a good job I went in holding his hand or else he could have been anybody." (Sue)
- "I thought oh god, with the pity on her face, it's just unbearable. She could see we were taking it, we were okay, we had come to terms with it and yet she was still pitying us. I wanted the facts and needed to know what would happen next. So I guess they need to adapt to who they have in front of them. I needed a more grown up approach." (Amy)
- "The hardest part of the experience for me was seeing the sonographer. I felt her patient care was not good. Although they see people like a conveyor belt, they just need to be a bit more, well the lady I saw could have been more sensitive." (Sally)
- "All the sonographer said was, are you sure you have got your dates right and that was how I knew everything wasn't okay. She said the lining of your womb, there is nothing there. That was how I found out. I thought are you saying I made this up? I have done tests, the urgent care centre did a test, my midwife did a test. I haven't made this up." (Sue)

Natalie stated that she did not want to see other women distressed and felt the nurses did a good job at '*hiding them away somewhere private.*' Although, when the sonographer directed her to a consulting room following her scan, Natalie did not know why she was there and left the EPAU after composing herself and went home. She received a telephone call from the nurse later that afternoon, asking her why she had left the unit and was asked to return to the EPAU. Some women attached a considerable significance to where they were asked to wait following their ultrasound scan as demonstrated in Claire's account, when she said '*she put me in a quiet room and I thought oh god that means that I am a sad case.*' However, it appears from the remainder of her quote (box 4) that this private room offered her a sense of comfort on another occasion as it gave her the space to cry in private.

Communication: some room for improvement

When the women spoke about how they were communicated with by the staff in the EPAU, there was an overwhelming sense that they valued being treated with respect and compassion, that they had time to talk to the nurse and ask questions, and felt that they had been listened too (box 5). However, three women in particular felt that their husbands, despite being present in the consulting room, were excluded from the conversation and their feelings about the miscarriage were not explored or respected. Both Sue and Amy spoke of the distress experienced by their partners. Amy's husband asked her to inform the researcher that there is no specific information available for men. He wanted to know what happens next, he wanted to ask questions and he wanted to know what he could do to help.

There was an overwhelming sense that the women wanted the EPAU staff to treat them as individuals and adapt their style of communication accordingly. Some women described how after several scans the actual confirmation of their miscarriage was not a surprise to them and they were not overtly emotional. However, some nurses in particular overly expressed their sympathy toward them, which was perceived as being inappropriate and untimely. In contrast, the sonographers were generally perceived to be uncaring and unsympathetic and several women described feeling as though they were on a conveyor belt, while being ignored. While the ultrasound scan was a routine procedure for the sonographer, it was not a common procedure for most of these women and they did not always know what was happening to them.

Additionally, some women described their distress at hearing the sonographer discuss their scan findings with other professionals in the ultrasound room, without directly communicating bad news to them. When the sonographer did speak to them directly, they were often considered to be insensitive and broke the news without compassion as Sue's accounts demonstrates in box 5.

Moving on

Women experienced loss differently following the miscarriage. Some were anxiously waiting for the physical process of miscarriage to end so that they could try to conceive again as soon as possible. Jayne thought that becoming pregnant again would somehow 'fix her'. Some participants believed that the pain would go away and they could live again following the miscarriage. Other women blamed themselves for the miscarriage and considered themselves a failure and Jayne felt completely

Box 6 Moving on

- "So immediately you are like ok let's get going again but at that point that's the only thing that you feel is going to fix it." (Jayne)
- "… you go from having closure and being relieved and then having a bad day and then a good day [cries]. It's just frustrating because I had hoped after the procedure that I would just feel better …. It's a slower process to recover than I probably thought it would be." (Sally)
- "I think even if it's a couple of days, it doesn't have to be straight away, when the shock has worn off to some extent and you have started to process what has happened, a quick phone call to me to say how are you … it would make a huge difference." (Sue)

humiliated by the whole experience but did not elaborate on this further.

Although all participants were given the contact details of local counsellors, none of the women took up the opportunity for counselling after their miscarriage. Only one woman contacted the Miscarriage Association for support but was advised that there was no support available in her local area. Interestingly, Claire and Kerry agreed to participate in this study because they felt it would be helpful for them to talk to the researcher about their experiences. They both acknowledged at the end of the interview that talking helped and that they needed to seek support from the local counselling service because they had no one else to talk to and wanted an opportunity to explore their unanswered questions (box 6).

Some women felt there was no appropriate service for them to access following their miscarriage. Women reported that their GPs did not follow up on their care. None of the women thought they could contact the EPAU following their miscarriage because they perceived this service to only be available while miscarrying. Equally, women felt unable to access the midwife as they were no longer pregnant.

For those women who wanted ongoing support some did not want contact with the EPAU team because they felt it would exacerbate unhappy memories. However, others believed it would have been helpful if one of the nurses had contacted them to ask how they were and to check that they did not have any unanswered questions.

DISCUSSION

The primary aim of this study was to explore how women perceive the provision of care and emotional support they receive in an EPAU, following a first trimester miscarriage, using a qualitative research approach. EPAUs were introduced to provide a dedicated healthcare service to women experiencing complications with early pregnancies, in a timely and efficient manner. However, evidence to support whether care has been improved following the implementation of these services is still limited[28] and it has been suggested that future studies should focus on what kind of early pregnancy care women would prefer to receive.[19] In this study, key themes emerged supporting the need for enhanced patient-centred care in the EPAU, as well as an unanticipated pattern or trend in the data indicating a need to enhance the provision of care for women with early pregnancy complications within and beyond the scope of the EPAU.

IPA is useful for helping expose the complexity of women's accounts through the various stages of their miscarriage experience and between women's accounts.[26] In the early phases, women mostly wanted a degree of hope and reassurance that they were not miscarrying, when they first presented to their GP or midwife. This is not an uncommon finding, and women will routinely search online forums, searching for news of positive pregnancy outcomes from women who are willing to share their experiential accounts, having experienced similar situations.[29] Additionally, women in this study spoke of needing this hope and reassurance to be balanced with honesty and realism, which can be an extremely difficult expectation to meet within the context of potential life and death discussions.[30] Women needed to know what would happen if they did miscarry and how they should manage this, and they needed to know what would happen to them on their first visit to the EPAU. While there is a considerable body of evidence encouraging healthcare professionals to share information and support understanding,[29 31 32] women in this study criticised their GPs for either being insensitive or for not providing adequate information.

This was significant because it is common practice for GPs and midwives to refer women to an EPAU following an initial clinical assessment. If a woman has not experienced a prior miscarriage, her knowledge of an EPAU service is going to be limited. National Institute for Health and Care Excellence (NICE) guidelines[28] recommend that women should be seen within 24 hours of referral to the EPAU. While this practice might be achieved in EPAUs where they operate a 24 hours service 7 days per week, some EPAUs do not follow this model and operate a more limited 09:00–17:00 service, Monday to Friday. It is, therefore, inevitable that some women will then have to wait for an appointment. In this study, some women had to wait 4 days for their appointment. Yet, evidence from this study and others indicates that waiting is difficult to endure and is associated with increased levels of anxiety, stress and uncertainty about the viability of one's pregnancy.[33] This is particularly exacerbated when a woman's knowledge of miscarriage is limited and they do not know what to expect should they miscarry[10 11] prior to their EPAU appointment. As evidenced in other studies, women mostly expect that their pregnancies will continue smoothly, maybe because of technological advances in medicine and few women consider the potential risk for miscarriage.[34]

Consistent with other studies,[35] once a diagnosis of miscarriage was confirmed, this was an emotionally burdensome time for women and their partners as they processed, adapted and responded to the information. Some women reported experiencing difficult and

emotionally challenging encounters with staff who failed to show them compassion and sensitivity and made them feel as though they were one of many women passing through the EPAU clinic in any one day. Fundamentally, we found that women were reluctant to complain openly to clinical staff, though the reasons for this are unclear. It is possible that they did not have the emotional resilience to challenge or question their care while undergoing a miscarriage. However, a socioecological model of resilience from a social and cultural context might influence their ability to cope, and similarly influence the ability of those providing care to support them.[36] However, these experiences were not forgotten and added to the women's level of distress, potentially constituting a barrier to their recovery. Criticism towards healthcare professionals for being insensitive, failing to show empathy and using trivialised comments within the context of threatened and actual miscarriage is not a new finding.[29 35]

Healthcare policy in the UK emphasises the importance of empowering patients to make informed decisions[37 38] and yet, patients are routinely dissatisfied with the level of information they receive.[10 39] In this study, women spoke of their partners and themselves routinely searching the internet for information to help them understand what was happening to them and to understand how the miscarriage may be managed. For some women in particular, the need for more graphic, detailed information intensified as they prepared for the possibility of a natural miscarriage. They wanted to know how much bleeding they were likely in incur, how much pain they were likely to experience and what steps they could take to make themselves more comfortable. Several women complained that their nurses were reticent to give them detailed information because everyone experienced miscarriage differently. Overwhelmingly, the need for explicit information was required but nurses often failed to meet the patient's information needs. Poor communication and lack of appropriate and tailored information is frequently identified in the literature[34 35] between women and their healthcare providers. Healthcare professionals need to take into account variations in people's need for information at any given time and respond accordingly.[29] It may be important to provide healthcare providers with advanced communication skills to ensure that they are trained to focus on the individual needs of the patient to show empathy, support and understanding and have skills and strategies to help them disclose what is often difficult and sensitive information. This has been undertaken in cancer services for a number of years and has proved beneficial.[40 41]

It was apparent from a number of other accounts that women perceived a lack of partnership between themselves and the nurses working in the EPAU in regards to facilitating a shared decision-making approach. Despite being given information to consider their options, at least 5 out of the 10 women spoke of feeling disempowered to make decisions. Yet, shared decision-making is considered to be the ideal model in healthcare practice to ensure that patients' perspectives and contribution to the decision have been considered and responded too accordingly and is often associated with improved patient outcomes and satisfaction with their care.[42] In this study, some reports indicate that even when patients are given information to explain various treatment or surgical options, they are often steered towards a practitioner's preferred option of management and the patient's preferences are discounted.[43 44] It is not clear from the evidence generated in this study why nurses were so proactive in leading decisions about the clinical management of miscarriage but even though we assume that people are more proactive in managing their care, these women complied with the decisions being made for them without challenging the nurse. However, protocols appeared to be in place determining who qualified for which mode of miscarriage management depending on the size of the gestational sac and how long it took to confirm the miscarriage had occurred.

A number of EPAUs rely on protocols driven by ultrasound measurements of gestational sacs and repeat scans to diagnose and confirm a miscarriage, but is critical of the level of detail provided in the NICE guidelines to help advise healthcare professionals about when to repeat scans and when to make final decisions about the viability of the pregnancy.[45] This is an important issue because two of the women participating in this study did not understand the relevance of measurements and one described feeling 'dehumanised' while waiting for repeat scans based on measurements alone. Women need to be told the relevance of these measurements and the best choice of care should not be dependent entirely on what is dictated by the clinical protocol but rather on the values, needs and preferences of the patient,[46] and the perceived advantages and disadvantages of the various options available to them.[47]

The findings in this study are limited to a small sample of women and cannot be considered representative of all women; however, the experiential accounts analysed demonstrate some convergence in women's accounts which are worthy of further exploration.

CONCLUSION

Findings from this study raise some important implications for managing the care of women and their partners from the point of seeking initial help from their midwife or GP through to the provision of care in the EPAU. Individualised care is required to ensure that women and their partners do not feel 'dehumanised' in a system that they do not understand. The provision of individualised care, respect for women's opinions and appropriate clinical information is imperative to those experiencing miscarriage. This is important because women respond to miscarriage differently. Furthermore, staff need to give equal consideration to women's emotional needs as well as their physical needs to help them relieve their level of distress which in turn may help their recovery after miscarriage.

Further research needs to focus on the provision of care from the point of initial contact with the GP or midwife and the transition of care to the EPAU to ensure that a streamlined, supportive and continuous care package is provided. These should not be considered as distinct provisions of care.

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REFERENCES

1. Rai R, Regan L. Recurrent miscarriage. *The Lancet* 2006;368:601–11.
2. National Institute for Health and Clinical Excellence. Ectopic Pregnancy and Miscarriage, NICE Quality Standard. 2014 Nice.org.uk/guidance/qs69
3. Musallam R, Salem N, Al Halol R, *et al*. Management of pregnancy loss in the first trimester: a retrospective audit. *Lancet* 2018;391(Suppl 2):S34.
4. Stephenson MD, Awartani KA, Robinson WPR. Cytogenetic analysis of miscarriages from couples with recurrent miscarriage: a case-control study. *Hum Reprod* 2002;17:446–51.
5. Regan L, Rai R. Epidemiology and the medical causes of miscarriage. *Baillieres Best Pract Res Clin Obstet Gynaecol* 2000;14:839–54.
6. Larsen EC, Christiansen OB, Kolte AM, *et al*. New insights into mechanisms behind miscarriage. *BMC Med* 2013;11:154.
7. Tur-Torres MH, Garrido-Gimenez C, Alijotas-Reig J. Genetics of recurrent miscarriage and fetal loss. *Best Pract Res Clin Obstet Gynaecol* 2017;42:11–25.
8. Laopaiboon M, Lumbiganon P, Intarut N, *et al*. Advanced maternal age and pregnancy outcomes: a multicountry assessment. *BJOG* 2014;121(Suppl 1):49–56.
9. Meaney S, Sheehan J, Rice R, *et al*. 950: The general populations' understanding of miscarriage: a cross sectional study. *Am J Obstet Gynecol* 2017;216:S537.
10. Meaney S, Corcoran P, Spillane N, *et al*. Experience of miscarriage: an interpretative phenomenological analysis. *BMJ Open* 2017;7:e011382.
11. Bayrampour H, Heaman M, Duncan KA, *et al*. Advanced maternal age and risk perception: a qualitative study. *BMC Pregnancy Childbirth* 2012;12:100.
12. Geller PA, Kerns D, Klier CM. Anxiety following miscarriage and the subsequent pregnancy: a review of the literature and future directions. *J Psychosom Res* 2004;56:35–45.
13. Adolfsson A. Applying Heidegger's interpretive phenomenology to women's miscarriage experience. *Psychol Res Behav Manag* 2010;3:75–9.
14. Condous G. Enough is enough! Time for a new model of care for women with early pregnancy complications. *Aust N Z J Obstet Gynaecol* 2008;48:2–4.
15. Papaioannou GI, Syngelaki A, Maiz N, *et al*. Ultrasonographic prediction of early miscarriage. *Hum Reprod* 2011;26:1685–92.
16. Edey K, Draycott T, Akande V. Early pregnancy assessment units. *Clin Obstet Gynecol* 2007;50:146–53.
17. Tsartsara E, Johnson MP. Women's experience of care at a specialised miscarriage unit: an interpretative phenomenological study. *Clin Eff Nurs* 2002;6:55–65.
18. Ockhuijsen HD, Boivin J, van den Hoogen A, *et al*. Coping after recurrent miscarriage: uncertainty and bracing for the worst. *J Fam Plann Reprod Health Care* 2013;39:250–6.
19. van den Berg MM, Goddijn M, Ankum WM, *et al*. Early pregnancy care over time: should we promote an early pregnancy assessment unit? *Reprod Biomed Online* 2015;31:192–8.
20. Wendt K, Crilly J, May C, *et al*. An outcomes evaluation of an emergency department early pregnancy assessment service and early pregnancy assessment protocol. *Emerg Med J* 2014;31:e50–e54.
21. Rowlands IJ, Lee C. 'The silence was deafening': social and health service support after miscarriage. *J Reprod Infant Psychol* 2010;28:274–86.
22. Gerber-Epstein P, Leichtentritt RD, Benyamini Y. The experience of miscarriage in first pregnancy: the women's voices. *Death Stud* 2008;33:1–29.
23. MacWilliams K, Hughes J, Aston M, *et al*. Understanding the experience of miscarriage in the emergency department. *J Emerg Nurs* 2016;42:504–12.
24. Lok IH, Neugebauer R. Psychological morbidity following miscarriage. *Best Pract Res Clin Obstet Gynaecol* 2007;21:229–47.
25. Laopaiboon M, Lumbiganon P, Intarut N, *et al*. Advanced maternal age and pregnancy outcomes: a multicountry assessment. *BJOG* 2014;121 Suppl 1:49–56.
26. Smith JA, Flowers R, Larkin M. *Interpretive phenomenological analysis: theory, method and research. Understanding method and application*. London, UK: Sage, 2009.
27. Furber L, Bonas S, Murtagh G, *et al*. Patients' experiences of an initial consultation in oncology: knowing and not knowing. *Br J Health Psychol* 2015;20:261–73.
28. National Institute for Health Clinical Excellence. *Ectopic pregnancy and miscarriage. Diagnosis and initial management in early pregnancy of ectopic pregnancy and miscarriage*: NICE Clinical Guideline, 2012:154.
29. Betts D, Dahlen HG, Smith CA, *et al*. A search for hope and understanding: an analysis of threatened miscarriage internet forums. *Midwifery* 2014;30:650–6.
30. van Vliet L, Francke A, Tomson S, *et al*. When cure is no option: how explicit and hopeful can information be given? A qualitative study in breast cancer. *Patient Educ Couns* 2013;90:315–22.
31. Silverman J, Kurtz S D. *Skills for communicating with patients*. 3rd edn. London: Radcliffe Publishing Ltd, 2013.
32. Sweeny K, Shepperd JA, Han PK. The goals of communicating bad news in health care: do physicians and patients agree? *Health Expect* 2013;16:230–8.
33. Boivin J, Lancastle D. Medical waiting periods: imminence, emotions and coping. *Womens Health* 2010;6:51–9.
34. Stephenson MD, Awartani KA, Robinson WP, *et al*. Cytogenetic analysis of miscarriages from couples with recurrent miscarriage: a case-control study. *Hum Reprod* 2002;17:446–51.
35. Rowlands IJ, Lee C, Chrina J. 'The silence was deafening': social and health service support after miscarriage. *J Reprod Infant Psychol* 2010;28:274–86.
36. Ungar M. Resilience, trauma, context, and culture. *Trauma Violence Abuse* 2013;14:255–66.
37. Department of Health. *Liberating the NHS: no decision about me without me*: Department of Health, 2010.
38. Jones P. *New care models: empowering patients and communities. A call for action for a directory of support*. London: Pollyana Jones, 2015.
39. Moohan J, Ashe RG, Cecil R. The management of miscarriage: results from a survey at one hospital. *J Reprod Infant Psychol* 1994;12:17–19.
40. Schofield NG, Green C, Creed F, *et al*. Communication skills of health-care professionals working in oncology--can they be improved? *Eur J Oncol Nurs* 2008;12:4–13.
41. Wilkinson S, Perry R, Blanchard K, *et al*. Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomised controlled trial. *Palliat Med* 2008;22:365–75.

42. Land V, Parry R, Seymour J. Communication practices that encourage and constrain shared decision making in health-care encounters: systematic review of conversation analytic research. *Health Expect* 2017;20:1228–47.
43. Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient Educ Couns* 2002;48:51–61.
44. Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16.
45. Bourne T. A missed opportunity for excellence: the NICE guideline on the diagnosis and initial management of ectopic pregnancy and miscarriage. *J Fam Plann Reprod Health Care* 2015;41:13–19.
46. CNO. *Compassion in practice: nursing midwifery & care staff our vision and strategy*. London: Department of Health, 2013.
47. Wallace RR, Goodman S, Freedman LR, *et al*. Counseling women with early pregnancy failure: utilizing evidence, preserving preference. *Patient Educ Couns* 2010;81:454–61.