ARTICLE IN PRESS

Midwifery ▮ (▮▮▮▮) ▮▮▮–▮▮▮

Contents lists available at SciVerse ScienceDirect

Midwifery

journal homepage: www.elsevier.com/midw

Information-hungry and disempowered: A qualitative study of women and their partners' experiences of severe postpartum haemorrhage

Claire Snowdon, BA, MA, PhD (Lecturer)[a,*], Diana Elbourne, BA, MSc, PhD (Professor of Healthcare Evaluation)[a], Mary Forsey, BSc, PhD (Trainee Clinical Psychologist)[b], Zarko Alfirevic, MD, FRCOG (Professor of Fetal and Maternal Medicine)[c]

[a] *Medical Statistics Department, London School of Hygiene and Tropical Medicine, Keppel Street, London, UK*
[b] *Division of Clinical Psychology, Institute of Psychology, University of Liverpool, Liverpool, UK*
[c] *Department of Women's and Children's Health, University of Liverpool, Liverpool, UK*

ARTICLE INFO

Article history:
Received 6 July 2011
Received in revised form
14 December 2011
Accepted 29 December 2011

Keywords:
Postpartum haemorrhage
Clinical trial
Qualitative

ABSTRACT

Objective: to explore how severe postpartum haemorrhage (PPH) and its management is experienced by women and their partners, and how they later view events.
Design: interpretive phenomenological qualitative study with semi-structured interviews.
Setting: in-depth interviews were conducted in participants' homes and focused on experiences of PPH in hospital and post-discharge.
Participants: nine women who had experienced severe PPH and six partners.
Findings: this study demonstrates the stressful and emotional nature of severe PPH and extends the literature by considering partners' perspectives. Women and men had different experiences and information needs, but interviewees often shared a common desire for help to understand past events. A dominant theme of communication difficulties, and two subthemes, disempowerment and information-deprivation arose strongly from the data. Communication difficulties were understandable during the emergency but were frustrating and upsetting in postpartum care and the longer term.
Conclusions and implications for practice: research is needed to develop better communication and supportive strategies, which might avoid the sense of disempowerment in this potentially vulnerable population. Different information and support needs for women and men should be considered whatever policies are implemented.

© 2012 Elsevier Ltd. All rights reserved.

Introduction

Postpartum haemorrhage (PPH) is a major cause of maternal death around the world, particularly in Africa and Asia where nearly one-third of pregnancy-related deaths are associated with haemorrhage (Khan et al., 2006). While maternal death is rare in the UK, PPH is one of the leading causes of mortality and morbidity in this setting (CMACE, 2011). PPH is often defined as blood loss in excess of 500 ml (WHO, 2003). Severe PPH is higher but in practice various definitions have been used. Severe PPH was, for instance, defined in an international trial of the management of the third stage of labour as measured blood loss $>1{,}000$ ml (Gulmezoglu et al., 2009), whereas a European survey used a higher level of measured blood loss $>1{,}500$ ml, which they found occurs in 4.6 per 1,000 deliveries (Zhang et al., 2005). Blood loss can however be difficult to measure and is often imprecisely estimated by clinicians (Razvi et al., 2008).

Our team aimed to develop a UK-based clinical trial of treatment for severe PPH and wished to understand the hospital context into which it would be introduced. Given the difficulties in defining severe PPH by blood loss, it was defined for the planned trial by the interventions used; by uterine tamponade, embolisation, laparotomy after vaginal delivery, suture, vessel ligation, or hysterectomy. These interventions, and the uncontrolled bleeding that characterise severe PPH, would suggest that massive PPH is likely to be a traumatic experience for women and their partners, and a challenging setting for the proposed clinical trial. Information about how women and partners experience the haemorrhage, management of the emergency and how they later view events, would therefore be a useful aid to inform development of the protocol for that trial (Snowdon et al. 2012).

Birth trauma more generally is a broad and multi-faceted phenomenon, which has been the focus of a substantial body of qualitative and quantitative research. Researchers have explored women's experiences of traumatic birth at the time of delivery,

* Corresponding author.
E-mail addresses: claire.snowdon@lshtm.ac.uk (C. Snowdon), diana.elbourne@lshtm.ac.uk (D. Elbourne), mforsey@liv.ac.uk (M. Forsey), zarko@liverpool.ac.uk (Z. Alfirevic).

0266-6138/$ - see front matter © 2012 Elsevier Ltd. All rights reserved.
doi:10.1016/j.midw.2011.12.012

Please cite this article as: Snowdon, C., et al., Information-hungry and disempowered: A qualitative study of women and their partners' experiences of severe postpartum haemorrhage. Midwifery (2012), doi:10.1016/j.midw.2011.12.012

highlighting feelings of panic, violation, loss of dignity, lack of care and communication, and negative thoughts (Mapp and Hudson, 2005; Ayers, 2007; Thomson and Downe, 2008; Elmir et al., 2010; Beck, 2011). The consequences of traumatic birth, the impact on relationships with partners and with babies (Ayers et al., 2006; Ayers, 2007; Nicholls and Ayers, 2007), breast feeding (Beck and Watson, 2008) and in particular the development of Post Traumatic Stress Syndrome (PTSS) (Creedy, 2000; Ayers and Pickering, 2001; Beck, 2004; Cohen et al. 2004) are well documented. Studies have also considered different types of traumatic experiences with the aim of understanding the particular features and circumstances associated with obstetric conditions (Van Pampas et al., 2004), events (Williams et al., 2005) and interventions (Emerson, 1998; Ryding et al., 1998), but the experience of severe PPH and its treatment remains under-explored.

Personal accounts (Birth Trauma Association Website: www.birthtraumaassociation.org.uk/birth_stories.htm#pph and The Third Stage of Labour Website; www.thirdstageoflabour.org/womenexperiences.html, www.thirdstageoflabour.org/mans_experience.html) and two qualitative studies offer some insights. One study considers effects of PPH on breast feeding, but does not specifically explore experiences of PPH (Thompson et al., 2010). The most relevant research involves women who underwent hysterectomy following PPH, and describes dramatic and stressful circumstances, as well as women's concern for their partners during the crisis (Elmir et al., 2011). We were unable to identify any studies, which include direct testimony from partners.

Qualitative research is particularly suited to exploring multiple perspectives (Lincoln and Guba, 2000) and sensitive or emotional subjects (Lee, 1993), and we undertook an interpretive phenomenological study (Lopez and Willis, 2004) to better understand experiences of severe PPH for women and their partners.

Methods

Sampling and recruitment

One obstetrician at each of two UK hospitals identified women from medical notes who had survived severe PPH between 2000 and 2005. They were asked to identify women whose PPH was indicated by the interventions they had received (uterine tamponade, embolisation, laparotomy after vaginal delivery, suture, vessel ligation, or hysterectomy), to mirror the eligibility criteria that would be used in the proposed trial.

Fifteen cases were identified. The obstetricians wrote to all 15 women to invite them and their partners to join the study. No reminders were sent. Nine women and six partners agreed.

Interviews

With interviewees' written consent, interviewers (CS, MF – both non-clinicians) conducted semi-structured interviews from September 2006 to January 2007. Interviews were recorded, fully transcribed and transcripts pseudonymised.

We took an interpretive phenomenological approach which emphasises the importance of context, sees personal experiences as socially situated and explores the meaning of experiences for individuals (Koch, 1995; Lopez and Willis, 2004). While some qualitative methods are designed to limit researcher influence on data collection and analysis, to 'bracket' out or put aside assumptions and theories (Gearing, 2004), this approach explicitly draws upon researcher expertise to probe and reflect upon data, and acknowledges the interpretive role. While the range of experiences are presented in detail, as faithfully as possible, the aim is to produce an account of a phenomenon which moves beyond descriptions of individual experiences and is capable of informing practice.

Interviews elicited and explored PPH narratives, offering interviewees opportunities to recall and explore issues of personal relevance. Three women were interviewed on their own and six were interviewed with their partners. There are methodological advantages and disadvantages of each approach. While individual interviews produce an account which is not subject to the modifying effects of a partner's presence, women interviewed alone could find it difficult to recall some details of their experience. In joint interviews partners worked together to produce careful accounts of their experiences, filling gaps or supplying details if their partner could not, and seeking out each other's views. This co-construction of a shared account (Seymour et al., 1995; Morris, 2001) appeared to be satisfying for interviewees, producing dynamic and discursive data and allowing their priorities to come to the fore. Although they recalled difficult times and emotions, no-one chose to end their interview.

Analysis

The members of the research team brought different skills to the analytical process. Two members of the team, CS and DE, were primarily responsible for analysis. CS is a qualitative researcher specialising in participants' views of perinatal trials; DE is a senior trialist familiar with qualitative research in this field. During the final stages of the analysis CS and DE drew on the clinical and trials experience of ZA, and MF's experience of qualitative research and her role in the interviews, to finalise the findings.

Post-interview notes summarised discussions and experiences of conducting the interview, and informed the initial analysis. Fully transcribed interviews were read by CS and DE, and entered into a textual analysis computer package, ATLAS.ti (Muhr, 1997). A coding frame was continuously refined in discussion by CS and DE as interviews were processed. Data were organised thematically and emergence of a dominant theme, *communication difficulties,* initiated further iterative and comparative cycles of analysis to explore this aspect of the data more closely.

Findings

Qualitative studies aim to represent a range of experiences (Mays and Pope, 1995) in order to capture different dimensions of a phenomenon. Clinical details provided by the women show that the sample includes singleton/twin deliveries, apparently straightforward/complicated deliveries, non-surgical/surgical interventions, resolved/recurrent bleeding, maternal admission to wards/High Dependency Units (HDU)/Intensive Care Units (ICU), neonatal admission to wards/Special Care Baby Units (SCBU)/Neonatal Intensive Care Units (NICU) (Table 1).

Analysis suggested four phases in the interviewees' experiences. The first, *unfolding crisis,* was the most dramatic. It also highlighted the *waiting time* for men as the PPH was managed; the *initial recovery period* for women; and *the longer term.* Women and men often discussed these phases from very different viewpoints.

Cross-cutting the four temporal divisions were dichotomous themes which included positive and negative aspects of experiences: *confidence/fear*, *trust/mistrust*, *satisfaction/dissatisfaction*. Within the last theme of dissatisfaction, one particular strand, *communication difficulties*, was of enormous importance, arising in each interview, even in predominantly positive accounts of care; in some it was a running theme throughout. Its significance was affirmed in each temporal phase. Further analysis defined two

Please cite this article as: Snowdon, C., et al., Information-hungry and disempowered: A qualitative study of women and their partners' experiences of severe postpartum haemorrhage. Midwifery (2012), doi:10.1016/j.midw.2011.12.012

Table 1
Clinical characteristics of women interviewed.

	Pregnancy and delivery			PPH management			Baby
Woman (partner)	Primiparous or multiparous	Planned CS	Emergency CS	Onset	Further surgery	Post-op. care	Condition and care
Annie (Paul)	Primipara, twins, term	✓		At delivery		Ward	Hypoglycaemic SCBU
Kirsty (Stephen)	Multipara, singleton, term		✓	At delivery	Iliac ligation	ICU	Normal
Sally (Frank)	Primipara, twins, term		✓*	At delivery		Ward	Normal
Ellen (Nigel)	Multipara, singleton, preterm		✓~	Antenatal/post-op		Ward	Preterm – 26 weeks NICU
Amy (David)	Multipara, singleton, term		✓#	Antenatal	Splenectomy	ICU	Seizures NICU
Kitty (Jerry)	Primipara, singleton, term		✓	At delivery		HDU	Normal
Pamela	Multipara, singleton, term		✓	At delivery		HDU	PrecautionarySCBU
Noreen	Multipara, singleton, preterm		✓~	Antenatal		HDU	Preterm – 29 weeks NICU
Stacey	Multipara, singleton, term	✓		At delivery	Hysterectomy	HDU	Normal

~ Placental abruption.
# Haemorrhage not in labour but resulted in ECS.
* Twin 1 born vaginally.

interlinked subthemes, *disempowerment* and *information deprivation*. The analytical structure that developed is shown in Fig. 1.

How communication difficulties are manifest in the different phases, and their relation to disempowerment and information deprivation, are presented below.

The unfolding crisis

Women and partners all described traumatic and frightening experiences. Three women with pre-delivery haemorrhage arrived at hospital by ambulance, bleeding heavily. Another four women bled during emergency caesarean sections after difficult labours, and two women bled after seemingly straightforward deliveries. Interviewees described a difficult and confusing time, with lots of activity, people running and sometimes shouting. For Noreen, who had a placental abruption at 29 weeks pregnant, the activity on arrival as an emergency, and a lack of communication, were disconcerting:

> [N]urses were just coming in, rushing in from God knows where, I mean I don't know how many there was and it felt like no one was telling me what was going on. I mean I was just lying there thinking 'Oh God, oh God, what's happening?' I suppose 'cos they were so concerned that I was bleeding so much…. [T]hey were putting like stuff in me hands and … because they wasn't talking to me, I was worried, I was panicking.

Noreen was unaccompanied as her partner was away from home at the time. She said that the anaesthetist who told her that she needed an emergency caesarean was the only person who spoke to her.

Ellen also underwent an emergency caesarean after a placental abruption when 26 weeks pregnant. She haemorrhaged again during surgery and again in the recovery room:

> I just remember lots of people … pummelling at my stomach in shifts, like two people at a time, pummelling my stomach. And I can remember it hurting and just actually trying to push them away.

Her partner, Nigel, gave more details:

> [J]ust as I was about to go in the room one of the doctors pulled me aside and let me know that she had taken a turn for the worse … When I went in, there were various times when there was up to ten or eleven people in there. …. There was two of them squeezing [the bags], they weren't letting them drip, they were forcing it in! … She was sort of drifting and totally oblivious to anything going on around her, on the verge of… losing consciousness.

Nigel was warned of the seriousness of the situation, but given no details about what had happened, or what clinicians were trying to do:

> They just said 'If you go in there, there is a lot of activity.' But they didn't really tell me what it was, or what their plans were. They just got on and did it.

Amy bled from her spleen at 38 weeks pregnant. Internal bleeding after an aneurysm was not evident, but she was in a lot of pain. She described arriving at hospital:

> I just remember them putting the monitors on me tummy to register the baby and … the doctor saying 'This baby's got to come out now!' …. it was just rush, rush, rush from that second. I was still on the trolley and pushed up a corridor and into, must have been, well it was an operating theatre…. [W]ithin seconds … people were tugging my clothes off me, my trousers, everything came off. Then I just remember cold on my tummy when they poured the iodine … ready to just open me up. My jewellery was pulled off, and they were trying to get my earrings out and I remember someone shouted 'Just leave them!' … And then I was basically just out and they shoved a mask on my face.

Amy inferred that she was about to have a caesarean:

> I understood that because they took me through to the theatre and I felt the coldness on me tummy. I thought 'They must be gonna cut me.' I just remember them saying 'Don't worry, don't worry.' They were all very nice, just saying basically 'Don't worry about it. Everything will be okay.' It wasn't an explanation, but I don't think they had time to give an explanation.

Amy's partner, David, was asked whether it would have been possible for her to have been involved in discussions about her care. He exclaimed:

> She was dying! … She wouldn't have been able to make any decisions. I know that because she just [wasn't] with us. She was out. She was dying in the ambulance.

Most women and partners portrayed themselves as passive participants in events beyond their control, with few expectations of involvement in discussions or decisions. Kirsty, who bled immediately after a difficult labour and emergency caesarean, and her partner Stephen, were typical in stating that there was no question of their involvement. Both were confident about the clinical decisions made on their behalf, and felt that staff had focused on clinical events. Stephen said:

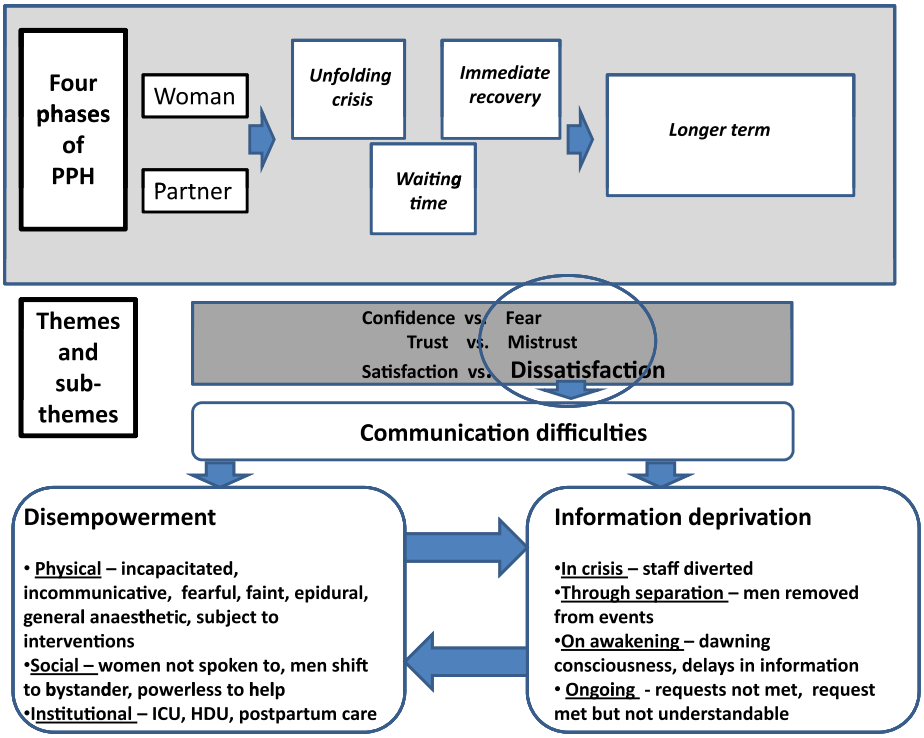

Fig. 1

> There wasn't any decisions to be made really. It was 'This is how things are.' I was along for the ride really. … I was just sort of so caught up in the whole thing, that it hadn't occurred to me that it could be any different…. I was happy to leave it in the hands of the professionals.

Annie was an important exception. She described an initial passive state followed by a strong need to engage with clinical decision-making. When she bled in the recovery room Paul was asked to leave. Annie was not undermined by this or the clinical activity around her and did not describe any of the panic and confusion that other women felt. Crucially she was able to talk to staff, initially as a coping mechanism:

> I just kept talking rubbish to them, just as a distraction and to keep me awake…. I felt actually quite relaxed and tired, and just thought there are so many people there and they all know what they're doing.

Then Annie started to engage with the implications of the situation:

> [I] thought 'Oh God I hope I don't die because they don't want to give me a hysterectomy'. Then I started saying 'if I need a hysterectomy don't worry, I mean I've got my twins, you know, I'm forty nearly, next year so I'd rather be around for them … so don't worry.

Annie managed to make her thoughts known and felt that it was this indication of her ability to process information that led to a discussion:

> It was at that point that someone, I think one of the doctors, actually just stopped and thought we need to tell her the other options.

Communication issues for men – the waiting time

While all accepted communication difficulties during the emergency, different feelings emerged about subsequent events. Men were asked to leave as the crisis developed. This could be a particularly difficult experience, exacerbated by lack of information.

Jerry was present at Kitty's caesarean, carried out as labour had not progressed. When she bled, he was asked to leave and was told that he could have their baby with him. He declined: '[I was] not feeling mentally strong enough to have the baby because I was just panicking too much about Kitty'. The operation took 5 hrs. While 'the information flow stopped completely,' Jerry's need for information increased:

> Within half an hour [of leaving] I was wanting to find out. Some of the nurses and the midwives … it was almost as though they were irritated by an anxious relative…. Everything was totally behind closed doors. I was completely on the outside… I didn't have a clue in terms of what ….options were available, what could happen, …what is happening, what has happened, exactly where the blood's coming from, what the risks are? There was no conversations around that at all.

He did receive what he felt was a good explanation from a junior doctor, but commented, 'It took me having to barrack them and having to constantly ask.'

When Annie bled, her partner Paul was 'disappointed' at having to leave:

> I was cut off from it and then suddenly I didn't know what was going on. … I felt I could just stand in the corner and watch and it wouldn't do any harm.

Please cite this article as: Snowdon, C., et al., Information-hungry and disempowered: A qualitative study of women and their partners' experiences of severe postpartum haemorrhage. Midwifery (2012), doi:10.1016/j.midw.2011.12.012

Their twins were hypoglycaemic and taken to SCBU. After 'ten or twenty minutes', Paul was told that Annie was being moved to another room. He heard no more for several hours:

> I went to ask how it was going and they said someone would come and see me. It was just forever. … I hadn't heard for a long period of time so obviously I had to assume that it wasn't going well and perhaps the worst case if they really haven't time to come and see me after all that time. I had to start thinking perhaps she was dying. … I was thinking how do I … bring up twins on my own.

He suggested a PPH information sheet would have helped, stating 'at least I would have known the situation. …That wouldn't have taken any more time for the staff.'

Kirsty was upset when Stephen was asked to leave when she bled during an emergency caesarean. 'I didn't want to be left alone. That was my last thought actually.' Stephen was taken to an empty delivery room:

> [I] sat down and then they brought [the baby] out. I held him and then I guess it was quite a long time, like over an hour, before they came. I remember seeing blood come up that had Kirsty's name on it so I realised then she was going through a fair amount of blood.

Stephen was given tea and a sandwich, but felt unable to eat or drink without provision for the baby. With no cot he felt he could not put him down. He described himself as 'desperate' for help with the baby so he could call relatives who were unaware that they were in hospital, and a neighbour who was looking after their son. He said:

> [I was] almost forgotten about, not entirely forgotten about, obviously there's a lot going on in a hospital and everyone's busy. … [I]t was easier to stick me in a quiet corner.

The first he heard was that Kirsty was in ICU post-surgery and the surgeon then put him 'fully in the picture.' She bled again that night and returned to theatre for iliac ligation.

Amy's partner David missed the delivery and arrived to find his family 'all crying':

> I thought she was dead … [T]hey took me into a side room … 'Got a baby daughter, but there's complications. Don't really know whether your missus is going to make it tonight. Just keep your fingers crossed.'… They never told me exactly what was wrong with her, just told me that she was seriously ill and they couldn't tell me [at] the moment. They'd get back to me. They got back to me five hours later.

These men felt forgotten. They appreciated that they were involved in an emergency, but felt undermined by the lack of communication and the sense that their practical and emotional needs were inadequately met.

Communication issues for women – initial recovery

All nine women underwent a caesarean, three with additional surgery. On waking they could be confused and in pain but still some reported a strong and immediate desire for information.

Kirsty felt she was given the information she needed from the earliest point in a form that she could process. She valued this very highly:

> [A]s I came round they must've been telling me over and over the same thing all the time … [I]t must've been going in because when they were talking to me when I was kind of, you know, conscious, I felt like I already knew most of it…. Obviously they were being very brief, that I'd gone back to theatre again and I'm in intensive care, I'd had lost a lot of blood and I'd still got my uterus and the baby's fine. And they [put] a photograph of the baby … in my hand.

Kirsty's situation was not typical and other women did not have such a positive experience. Noreen woke not knowing where she was or whether her baby had survived:

> I remember just being in this big room, I don't know what room it was and there was a nurse in there or a midwife at a desk but there was no like machines or nothing like breathing machines. I did have an oxygen mask on, I remember that.
>
> … I remember waking up and I was completely out of it, like in and out, in and out. My husband was there. He was crying and I thought 'Oh God, what's happened? Has – you know – is everything alright?' … It must have been … a good few hours afterwards, I said to them, 'Is my baby okay?' They explained like she was on a ventilator for about two or three hours … [and then] was breathing by herself.

Kitty's emergency caesarean was carried out with an epidural after labour failed to progress but, on bleeding, she was anaesthetised. She woke on HDU alone:

> It started coming back to me. I started thinking something really bad has happened. … My mouth was extremely dry, I felt awful. I called a nurse and said 'can you tell me what's happened?' She said 'Just wait. Your baby's there. Your baby's fine.' I had all kinds going through my head… I thought 'something's wrong with *me* then! … I've had a hysterectomy and they're not telling me!'… [S]omeone should have told me immediately what had happened, but they left me there twenty minutes before anyone came [but] when they did it was the nurse [again] who said 'Oh the doctor will talk to you soon.' I was asking for me partner at that point, I was saying 'Oh I wanna see my partner, I wanna see my mum, I wanna see somebody!'

Sally's delivery was difficult with forceps delivery of the first twin and a caesarean for the second; a PPH followed. Sally gave an emotional account of events post-delivery. After her partner Frank left, she had struggled on being moved at night with her twins:

> I was really distressed. … They took me to a ward, which was in darkness, you know, at that time of night all the lights are off. They wheeled me right down to the end and they said 'There's your bed' and left me. … Now can you imagine, (sighs) … I'd had fairly major surgery you know 24 hours before, nobody had explained to me what had happened, nobody had told me where I was. I was so surprised to be on a ward with other people. All the curtains were closed and I actually got out and said 'I'm really sorry everybody I've had twins and they're screaming and I know they'll keep everyone awake.' I didn't realise it was full of other people who just had… just given birth as well. I thought 'God where am I?'

Sally and Frank wanted to talk to a doctor. Sally was told that someone would speak to her. She thought it would be the surgeon who had managed her caesarean and PPH. No-one came and she was left feeling angry, without the explanation she felt she needed:

> If somebody had done what they had said they were going to do … I could forgive …. that they were short-staffed, that there wasn't enough equipment, that nobody really told me what was going on …. I can forgive all that because these

things happen but I would have liked to have someone to go through it with me.

Frank also felt events were difficult to understand:

[T]he next morning I asked for an explanation as to what had happened. I said I wouldn't leave unless they explained because I wanted to know what happened, basically to make sense of it all. …We were told that somebody would speak to us but they never did.

Stacey woke on HDU after a planned fourth caesarean under general anaesthetic, shocked to learn that she had bled and had undergone a hysterectomy. She had requested sterilisation but was 'really devastated' by the hysterectomy. She wanted to know what had happened and kept pushing for information. She was given information on several occasions but not in a way she could understand. First she saw the surgeon:

[He] just came in and said … 'the whole of your insides of your stomach have come away and basically the only thing that was holding the baby in was the waters and the placenta' and that was it, he flounced back off again.

Stacey asked for her notes: 'I didn't understand hardly anything. I would have liked someone to have gone through them with me.' She then asked to see a particular consultant who came to see her on the ward but by this time she was overwhelmed:

I had lots of questions in my head to ask her but when she come … she just like said stuff to me and I was just sitting there going like this (nodding) and I just said 'can I go home?' and she said 'yeah'.

Noreen described similar difficulties with the information she was given shortly after coming round from surgery:

It was someone in a gown. It might have been the surgeon … but because I was out of it, in and out of it, it just didn't register.

Communication issues – the longer term

Ellen was unusual in not wanting information about events surrounding the PPH. Although her partner Nigel, tried to explain and to describe his own 'traumatic' experiences, Ellen wanted to 'move on':

Normally I want to know all the information…. but I was just concentrated on [the baby] and [our son]. … I suppose I didn't matter.

She deliberately focused thoughts away from the implication of events, in particular the impact her death would have had on her family.

For most interviewees, information needs extended into the longer term. For Noreen practical issues made accessing information difficult. English was not her husband's first language and he was unable to fully understand the explanation given at the time. She was not able to assimilate the information and explain events to him. He did seek and secure some information but it took approaching two months to access a translator.

For Kitty her continued lack of understanding was 'a big problem':

I was never debriefed properly. I don't know what happened during them days. … It was all coping with the trauma and coping with the new baby …it probably took me till about six to eight months to actually come up with some of these questions that I wanted answers to, that Jerry couldn't answer 'cos obviously he didn't know the technicalities of it. So I feel like I've been left quite ignorant …. To this day I don't know what's happened.

Stacey also felt that it would have been helpful to talk to someone:

It just would have been nice for them to … acknowledge that it had happened to me … I felt like I was just pushed out the hospital 'cos they discharged me at 11 o'clock at night and …it was 'see ya!'.

Several interviewees described what they felt were problematic aspects of their care or mismanagement of events. Some tried for some time to find out what happened. Kitty and Jerry were suspicious when they were not given the details they wanted. To Kitty things seemed 'hush-hush':

I felt really like [the obstetrician] wasn't giving me the full facts … when he was saying that it was a common thing that happens. I knew it wasn't a common thing but I wasn't … in the right mind to challenge it at that time.

Pamela was also suspicious because she felt that her midwife and surgeon were 'hiding' from her. Another senior doctor came to tell her what had happened. She said she was still upset about this and that speaking to them might have helped.

It was not easy to request information and some women felt vulnerable. Sally commented: 'I really felt bullied like I couldn't complain, I couldn't do anything.' Frank added: 'I didn't feel like I could say anything either.' Sally felt that her inability to access information, and to protest the lack of support, had had a lasting effect:

[It] has affected the way that I think about myself, the way I conduct myself, my life everything, because I've never got over that anger with myself for putting up with what I put up with there. I was just a complete victim.

Discussion

This study confirms previous research findings, describing the stressful, emotional nature of severe PPH (Elmir et al., 2011), and extends the evidence base by considering partner perspectives and the context and consequences of PPH management. Two linked core features, *disempowerment* and *information-deprivation*, arose strongly from the data.

Women experienced severe PPH as disempowering on several levels. Their condition required rapid intervention often without room for the usual rules of clinical engagement. They were incapacitated to varying degrees, and those unable to speak felt they were not spoken to. They were however able to think, even on the edge of consciousness, and described unvoiced questions about where they were and what was happening. Most were inactive in the frenetic action around them, inferring the seriousness of the situation from what was happening to their bodies; clothes being removed, preparation for surgery, painful uterine massage. Feelings of being overpowered by people or circumstances could extend into the postnatal period, when women could feel helpless and vulnerable.

Men witnessing traumatic scenes feared for their partner's life but were rendered passive observers, powerless to help. Once excluded from events and cut off from any feedback, they were unable to secure explanations, and saw themselves as a low priority for staff.

These features are shared with other extreme emergency situations (O'Brien and Fothergill-Bourbonnais, 2004; Bremer et al., 2009a, 2009b) but here interviewees were especially affected by their confluence with specific features of their PPH

experience; involuntary separation and exclusion of partners, anxiety about newborns and their future, and difficulties in caring for babies for women still in recovery.

Information deprivation exacerbated the PPH experience, even for those satisfied with their treatment and grateful for a positive outcome. Women moved through the care of different staff in different locations, through labour, emergency delivery, post-operative and postpartum care. Men were displaced and rapidly changed roles from birth-partner, bystander, outsider, to post-partum supporter. In such shifting circumstances they rarely felt that staff addressed their information needs. Dissatisfaction with postpartum care, including communication difficulties, has been identified in several studies (Martell, 2003; Rudman and Waldenström, 2007; Persson et al., 2011) but this study suggests that a disconnect between various phases of care exacerbated the situation. Interviewees felt that staff in one setting did not always appreciate what they had been through in another, and it could be difficult to draw obstetricians and midwives into postoperative or postpartum care for effective explanations. While interviewees accepted communication difficulties during an emergency, they keenly felt information deficits once the emergency had passed. Where explanations were given, however brief and whatever the capacity for understanding, they were appreciated.

Disempowerment and information deprivation may be underlying features of PPH, a result of incapacity and the need for rapid clinical intervention. It seems however that they were heightened rather than assuaged by the management of the clinical context in which PPH plays out. We offer several data-led suggestions for strategies, which may be developed to ameliorate some of the difficulties described.

One of the interviewees, Paul, suggested that a basic PPH leaflet would be very helpful. If kept on the standard PPH theatre trolley, leaflets would be readily available for partners asked to leave as a PPH develops, or given to those arriving during the emergency. This would address initial information deficits and may dispel some feelings of abandonment, but information about PPH is complex and may be challenging and frightening. If it is to be given to relatives in an emergency with limited opportunities for back-up from staff, it is important that it is developed carefully and its use monitored and assessed.

We suggest that it may be timely to consider whether partners do need to leave the room in all situations. This has been widely debated over the last decade with reference to emergency room resuscitations (Eichhorn et al., 2001; MacLean et al., 2003; Critchell and Marik, 2007; Howlett et al., 2010) where some well-developed 'family presence' programmes are now in place (Booth et al., 2004; Lowry, 2011). Although there is evidence of benefits to patients, family members and staff (for review see Hodge and Marshall, 2009), and studies show that patients and relatives often wish to stay together (Benjamin et al., 2004; Duran et al., 2007), this is not common practice in relation to obstetric emergencies. First-hand experience of events and the efforts that are made on their partners' behalf may give partners a sense of inclusion in the situation, rather than the exclusion described in our study. A partner's presence can be supportive for women in fear of their lives (Mapp and Hudson, 2005) and separation can be distressing: Elmir et al. (2011) poignantly describe a partner crying and asking to give his wife 'a last kiss' before having to leave. In our study Kirsty was fearful when she realised Stephen was leaving, and Paul wanted to stay with Annie. Family presence will not suit all couples, and it may be a logistic and interpersonal challenge for staff, but debate and the production of observational and qualitative data in this area would be helpful.

Counselling or debriefing, carefully integrated with care, may be appropriate after PPH. Most interviewees repeatedly articulated a need to discuss events, to fill the gaps where they could not account for what happened to them or their partner. Our interviews offered an opportunity to revisit events, but a health professional's assistance would be needed to assemble a complete and understandable story. Clinicians could offer a 'holding' debrief as soon as possible, with a commitment to giving detailed explanations once relevant information such as clinical results and adverse events reviews are available. Women and their partners could be encouraged to write down questions and highlight specific areas where they would like more information in anticipation of a formal opportunity to discuss events. This approach would require further research as debriefing after traumatic birth has been suggested as beneficial (Lavender and Walkinshaw, 1998), but benefits have not been replicated (Priest et al., 2003; Small et al., 2006). Counselling has also been recommended after birth trauma but with the caveat that specialist training and an improved evidence base for efficacy are required (Gamble and Creedy, 2004, 2009).

These various strategies may be brought together through the use of a 'family facilitator,' a member of staff assigned to enable relatives to stay with their partners during the management of an emergency (Hodge and Marshall, 2009), who may also provide ongoing information after the event. Helping men to understand events as they unfold and play out may allow them to offer information and ongoing support to their partners. The facilitator could be a named contact for questions from both partners in the aftermath, and could co-ordinate counselling or debriefing by other clinicians.

This study has yielded rich data from interviewees who clearly expressed their sense of disempowerment and their need for information. There were however counter-currents, which are also informative. Annie was able to articulate her wishes regarding hysterectomy to clinicians and her testimony highlights the importance of facilitating women's communication during the emergency where possible. Ellen was clear in recovery and the longer term that, for her, information about PPH was undesirable. These minor threads in the data are important reminders of the need to consider the range of responses in developing communication, information and support strategies in this challenging area of maternity care. For the strategies we suggest to be supportive and useful, variety in views and experience, as well as issues of timing, content and resource implications, must be taken into account.

Conclusions

Although the number of interviewees in this two-hospital UK study is small, it illuminates the PPH experiences of women and their partners. It highlights a number of ways in which they were disempowered by actions and events, and their strong desire for information. This is particularly valuable as interviewees often felt unable to make their information needs clear to staff at the time or afterwards.

We suggest several strategies but these require further study. Developing the means to attend to disempowerment and information deprivation around PPH is undoubtedly difficult, but the accounts presented here suggest that it is important for the well-being of women and their partners that these challenges are addressed.

Disclosure of interests

The authors declare no conflict of interests.

Contribution to authorship

CS, DE and ZA designed the study. Data were collected by CS and MF. DE and ZA were consulted throughout data collection for

direction and clarification. CS conducted the qualitative analysis in consultation with DE and prepared the first draft of the paper. DE and ZA reviewed the first draft and further developed interpretation of the findings and extended the discussion. All authors approved the final version of the paper.

Ethics

This study was approved by the Cambridge Multicentre Research Ethics Committee (Ref 06/Q0108/40 30-03-2006), Liverpool Research Ethics Committee (Ref AB/66240/1, 16-05-2006) and the Research and Development offices for the two clinical centres involved.

Funding

This study was supported with funds from the School of Reproductive and Developmental Medicine, University of Liverpool and carried out while CS received a joint ESRC/MRC fellowship. CS was accommodated by the Centre for Family Research, University of Cambridge during the study.

Acknowledgements

Professor Tina Lavender, Professor Gordon Smith, Ms Fatemeh Hoveyda and Dr Christoph Lees helped to set up the study. Professor Rona McCandlish and Dr Gill Gyte acted as study advisors. We are grateful to the women and men who participated in the interviews and were so generous with their time. Dr Gail Ewing and Dr Iain Chalmers commented on drafts of the paper.

References

Ayers, S., 2007. Thoughts and emotions during childbirth: a qualitative study. Birth 34 (3), 253–263.
Ayers, S., Eagle, A., Waring, H., 2006. The effects of childbirth related PTSD on women and their relationship: a qualitative study. Psychology, Health and Medicine 11 (4), 389–398.
Ayers, S., Pickering, AD., 2001. Do women get posttraumatic stress disorder as a result of childbirth? A prospective study of incidence. Birth 28 (2), 111–118.
Beck, C.T., 2004. Post-traumatic stress disorder due to childbirth – the aftermath. Nursing Research 53 (4), 216–224.
Beck, C.T., 2011. A metaethnography of traumatic childbirth and its aftermath: amplifying causal looping. Qualitative Health Research 21 (3), 301–311.
Beck, C.T., Watson, S., 2008. Impact of birth trauma on breast-feeding: a tale of two pathways. Nursing Research 57 (4), 228–236.
Benjamin, M., Holger, J., Carr, M., 2004. Personal preferences regarding family member presence during resuscitation. Academic Emergency Medicine 11 (7), 750–753.
Booth, M., Woolrich, L., Kinsella, J., 2004. Family witnessed resuscitation in UK emergency departments: a survey of practice. European Journal of Anaesthesiology 21, 725–728.
Bremer, A., Dahlberg, K., Sandman, L., 2009a. To survive out-of-hospital cardiac arrest: a search for meaning and coherence. Qualitative Health Research 19 (3), 323–338.
Bremer, A., Dahlberg, K., Sandman, L., 2009b. Experiencing out-of-hospital cardiac arrest: significant others' lifeworld perspective. Qualitative Health Research 19 (10), 1407–1420.
Centre for Maternal and Child Enquiries (CMACE), 2011. Saving mothers' lives: reviewing maternal deaths to make motherhood safer: 2006–08. The eighth report on confidential enquiries into maternal deaths in the United Kingdom. British Journal of Obstetrics and Gynaecology 118 (suppl. 1), 1–203.
Cohen, M.M., Ansara, D., Schei, B., Stuckless, N., Stewar, D.E., 2004. Posttraumatic stress disorder after pregnancy, labor and delivery. Journal of Women's Health 13 (3), 315–324.
Creedy, D.K., 2000. Childbirth and the development of acute trauma symptoms: incidence and contributing factors. Birth 27 (2), 104–111.
Critchell, C.D., Marik, P.E., 2007. Should family members be present during cardiopulmonary resuscitation? A review of the literature. American Journal of Hospice and Palliative Care 24 (4), 311–317.
Duran, C., Oman, K., Jordan, J., Koziel, V., Szymanski, D., 2007. Attitudes toward and beliefs about Family presence: a survey of healthcare providers, patients' families, and patients. American Journal of Critical Care 16 (3), 270–279.
Eichhorn, D.J., Meyers, T.A, Guzzetta, C.E., Clark, A.P., Klein, J.D., Calvin, A.O., 2001. Family presence during invasive procedures and resuscitation: hearing the voice of the patient. American Journal of Nursing 101 (5), 48–55.
Elmir, R., Schmied, V., Jackson, D., Wilkes, L., 2011. Between life and death: women's experiences of coming close to death, and surviving a severe postpartum haemorrhage and emergency hysterectomy. Midwifery Jan 18 [epub ahead of publication].
Elmir, R., Schmied, V., Wilkes, L., Jackson, D., 2010. Women's perceptions and experiences of a traumatic birth: a meta-ethnography. Journal of Advanced Nursing 66 (10), 2142–2153.
Emerson, W.R., 1998. Birth trauma: the psychological effects of obstetrical interventions. Journal of Prenatal and Perinatal Psychology & Health 13 (1), 11–44.
Gamble, J., Creedy, D., 2004. Content and processes of postpartum counseling after a distressing birth experience: a review. Birth 31 (3), 213–218.
Gamble, J., Creedy, D.K., 2009. A counselling model for postpartum women after distressing birth experiences. Midwifery 25 (2), e21–e30.
Gearing, R.E., 2004. Bracketing in research: a typology. Qualitative Health Research 14, 1429.
Gulmezoglu, A.M., Widmer, M., Merialdi, M., et al., 2009 Active management of the third stage of labour without controlled cord traction: a randomized non-inferiority controlled trial. Reproductive Health, 9;6:2.
Hodge, A.N., Marshall, A.P., 2009. Family presence during resuscitation and invasive procedures. Collegian 16 (3), 101–118.
Howlett, M.S., Alexander, G.A., Tsuchiya, B., 2010. Health care providers' attitudes regarding family presence during resuscitation of adults: an integrated review of the literature. Clinical Nurse Specialist 24 (3), 161–174.
Khan, K.S., Wojdyla, D., Say, L., Gulmezoglu, A.M., van Look, P.F.A., 2006. WHO analysis of causes of maternal death: a systematic review. Lancet 367 (9516), 1066–1074.
Koch, T., 1995. Interpretive approaches in nursing research: the influence of Husserl and Heidegger. Journal of Advanced Nursing 21 (5), 827–836.
Lavender, T., Walkinshaw, S.A., 1998. Can midwives reduce postpartum psychological morbidity? A randomized trial. Birth 25, 215–219.
Lee, R., 1993. Doing Research on Sensitive Topics. Sage Publications, London.
Lincoln, Y.S., Guba, E.G., 2000. Paradigmatic controversies, contradictions, and emerging confluences. In: Denzin, N.K., Lincoln, Y.S. (Eds.), Handbook of Qualitative Research, 2000. Sage Publications, London.
Lopez, K.A., Willis, D.G., 2004. Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. Qualitative Health Research 14 (5), 726–735.
Lowry, E., 2011. "It's Just What We Do": a qualitative study of emergency nurses working with well-established family presence protocol. Journal of Emergency Nursing Apr 21.
MacLean, S., Guzzetta, C., White, C., Fontaine, D., Eichhorn, D., Meyers, T., Desy, P., 2003. Family Presence during cardiopulmonary resuscitation and invasive procedures: practices of critical care and emergency nurses. American Journal of Critical Care 12 (3), 246–257.
Mapp, T., Hudson, K., 2005. Feelings and fears during obstetric emergencies – 1. British Journal of Midwifery 13 (1), 30–35.
Martell, L.K., 2003. Postpartum women's perceptions of the hospital environment. Journal of Obstetric, Gynecologic and Neonatal Nursing 32 (4), 478–485.
Mays, N., Pope, C., 1995. Rigour and qualitative research. British Medical Journal 311, 109.
Morris, S.M., 2001. Joint and individual interviewing in the context of cancer. Qualitative Health Research 11, 553–567.
Muhr, T., 1997. ATLAS.ti. Scientific Software Development, Berlin.
Nicholls, K., Ayers, S., 2007. Chilbirth related post traumatic stress disorder in couples: a qualitative study. British Journal of Health Psychology 12 (Pt. 4), 491–509.
O'Brien, J.A., Fothergill-Bourbonnais, F., 2004. The experience of trauma resuscitation in the emergency department: themes from seven patients. Journal of Emergency Nursing 30 (3), 216–224.
Persson, E.K., Fridlund, B., Kvist, L.J., Dykes, A.K., 2011. Mother's sense of security in the first postnatal week: interview study. Journal of Advanced Nursing 67 (1), 105–116.
Priest, S.R., Henderson, J., Evans, S.F., Hagan, R., 2003. Stress debriefing after childbirth: a randomised controlled trial. Medical Journal of Australia 178, 542–545.
Razvi, K., Chua, S., Arulkumaran, S., Ratnam, S.S., 2008. A comparison between visual estimation and laboratory determination of blood loss during the third stage of labour. Australian and New Zealand Journal of Obstetrics and Gynaecology 36 (2), 152–154.
Rudman, A., Waldenström, U., 2007. Critical views on postpartum care expressed by new mothers. BMC Health Services Research 7, 178.
Ryding, E,L., Wijma, K., Wijma, B., 1998. Experiences of emergency cesarean section: a phenomenological study of 53 women. Birth 25 (4), 246–251.
Seymour, J., Dix, G., Eardley, T., 1995. Joint Accounts: Methodology and Practice in Research Interviews with Couples. Social Policy Research Unit, University of York.
Small, R., Lumley, J., Toomey, L., 2006 Midwife-led debriefing after operative birth: four to six year follow-up of a randomised trial [ISRCTN24648614]. BMC Medicine 2006 March 1;4:3.

ARTICLE IN PRESS

Snowdon, C., Elbourne, D., Forsey, M.L., Alfirevic, Z., 2012. Views of Emergency Research (VERA): A qualitative study of women and their partners' views of recruitment to trials in severe postpartum haemorrhage. Midwifery. doi:10.1016/j.midw.2011.11.009.

The Third Stage of Labour Website. Women's Experiences of Having a Postpartum Haemorrhage in Their Own Words. 〈www.thirdstageoflabour.org/womenexperiences.html〉.

The Third Stage of Labour Website. A Husband's Experience of Postpartum Haemorrhage. 〈www.thirdstageoflabour.org/mans_experience.html〉.

Thomson, G., Downe, S., 2008. Widening the trauma discourse: the link between childbirth and experiences of abuse. Journal of Psychosomatic Obstetrics and Gynaecology 29 (4), 268–273.

Thompson, J.F., Heal, L.J., Roberts, C.L., Ellwood, D.A., 2010. Women's breastfeeding experiences following a significant primary postpartum haemorrhage: a multicentre cohort study. International Breastfeeding Journal 5, 5.

Van Pampas, M.G., Wolf, H., Weijmar Schultz, W.C., Neeleman, J., Aarnoudse, J.G., 2004. Post traumatic stress disorder following pre eclampsia and HELLP syndrome. Journal of Psychosomatic Obstetrics and Gynaecology 25 (3–4), 183–187.

Williams, A., Lavender, T., Richmond, D.H., Tincello, D.G., 2005. Women's experiences after a third-degree obstetric anal sphincter tear: a qualitative study. Birth 32 (2), 129–136.

World Health Organization, 2003. The Prevalence of Anaemia in Women: A Tabulation of Available Information. World Health Organization, Geneva. 2003.

Zhang, W., Alexander, S., Bouvier-Colle, M.H., Macfarlane, A., 2005. Incidence of severe pre-eclampsia, postpartum haemorrhage and sepsis as a surrogate marker for severe maternal morbidity in a European population-based study: the MOMS-B survey. British Journal of Obstetrics and Gynaecology 112 (1), 89–96.

Please cite this article as: Snowdon, C., et al., Information-hungry and disempowered: A qualitative study of women and their partners' experiences of severe postpartum haemorrhage. Midwifery (2012), doi:10.1016/j.midw.2011.12.012