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Title:

Women's safety alerts in maternity care: is speaking up enough?

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Abstract

Patients' contributions to safety include speaking up about their perceptions of being at risk. Previous studies have found that dismissive responses from staff discouraged patients from speaking up. A Care Quality Commission investigation of a maternity service where serious incidents occurred found evidence that women had routinely been ignored and left alone in labour. Women using antenatal services hesitated to raise concerns that they felt staff might consider irrelevant.

The Birthplace in England programme, which investigated the quality and safety of different places of birth for 'low risk' women, included a qualitative organisational case study in four NHS Trusts. The authors collected documentary, observational and interview data from March to December 2010 including interviews with 58 postnatal women. A framework approach was combined with inductive analysis using NVivo8 software.

Speaking up, defined as insistent and vehement communication when faced with failure by staff to listen and respond, was an unexpected finding mentioned in half the women's interviews. Fourteen women reported raising alerts about safety issues they felt to be urgent. The presence of a partner or relative, and receiving continuity of care, were facilitating factors for speaking up. Several women described distress and harm that ensued from staff failure to listen.

Women are speaking up, but this is not enough: organisation-focused efforts are required to improve staff response. Further research is needed in maternity services as well as acute and general health care on the effectiveness of safety-promoting interventions including real-time patient feedback, patient toolkits and patient-activated rapid response calls.

INTRODUCTION

There has been increasing interest internationally in the ability of patients and their families to contribute to their own safety (Vincent and Coulter 2002; Crock 2010; ACSQHC 2011). There is some evidence that patients can detect suspected adverse events earlier than professionals (Egberts *et al.* 1996). However, most interventions have focused on educating patients and encouraging them to question staff on pre-established issues such as hand washing and medication (Hall *et al.* 2010). Patients' readiness to speak up was substantially affected by the quality of their relationships with staff (Entwistle *et al.* 2010). Many were reluctant to challenge professionals because of previous experiences of not being heard or having their input belittled, or fear of victimisation (Coulter and Ellis 2006; Davis *et al.* 2008; Davis *et al.* 2011; ledema *et al.* 2012; Doherty *et al.* 2012).

Less is known about the role of women speaking up in maternity services. A study of interaction in antenatal clinics found that women used indirect ways to broach issues that worried them, feeling that they might not be considered valid by health professionals (McCourt 2006). Women's narratives about birth trauma referred to professionals' neglect of communication and their own feelings of powerlessness (Beck 2006). In an investigation of a maternity service where serious incidents had occurred, the Care Quality Commission documented cases of women "routinely being ignored and their description of their labour being dismissed by staff; being left alone for long periods of time while in labour; being spoken to rudely by staff; and not receiving adequate pain relief" (Care Quality Commission 2011). UK media have reported on incidents where staff failed to attend to labouring women's safety alerts (*Kent Messenger* 2010; Randhawa 2010, 2011; Boseley 2011). A report on stillbirths and neonatal deaths found that many bereaved parents had suspected something was wrong and had raised alerts which staff did not consider to be valid (Sands 2012).

The Birthplace in England research programme was designed to provide a solid evidence base regarding the quality and safety of different places of birth for 'low risk' women. The seven component studies aimed to map the configuration of maternity services; compare perinatal and maternal outcomes by planned place of birth at the start of care in labour (Birthplace in England Collaborative Group 2011); compare cost-effectiveness of birth settings; and investigate factors related to service organisation and staffing which are associated with the quality of maternity services, especially during transfer and escalation of care.

The qualitative organisational case studies (McCourt *et al.* 2011) provided insights into staff and user experiences. One unexpected finding was the frequency of women's accounts about speaking up to staff during antenatal, intrapartum or postnatal care. This paper focuses on situations in which women felt the need to speak up, and on the distress and harm that ensued when staff failed to respond in a timely way.

METHODS

Study aim and design

Birthplace case studies were carried out in four NHS Trusts across England to explore the policies and frontline practices through which organisations aim to improve safety and quality of care (McCourt *et al.* 2011). Sites were selected among the Trusts that were most highly ranked in Healthcare Commission assessments of maternity services (HCC 2008). Further selection criteria were variation in geographical location (inner-city, urban, suburban and rural); Index of Multiple Deprivation in the population served (low, moderate and high); and service configuration covering different combinations of obstetric units (OU), alongside midwifery units (AMU) and/or freestanding midwifery units (FMU). The sampling frame with characteristics of the four sites is shown in Appendix 1.

The study's approach was guided by Institute of Medicine definitions of quality as comprising six dimensions: safety ('avoiding injuries to patients from the care that is intended to help them'), effectiveness, timeliness, efficiency, equity and patient-centredness (IOM 2001). To enrich this framework we explored local meanings of quality and safety in the accounts of users and providers.

The semi-structured interview schedule (Appendix 2) was phrased in broad terms to inductively explore respondents' experiences without introducing notions they might feel drawn to repeat. Women could frame their narratives differently in response to questions such as: "How was the birth experience for you?" and "Is there anything you wish had been different about the care you received?". At an early stage of fieldwork we noted spontaneous references to speaking up in several interviews. As with other emerging topics, interviewers prompted women to recall details and draw conclusions from their experience by asking: "Can you tell me more about that?" and "What do you think about that now?".

Data collection

The study team was composed of four health service researchers (social scientists): principal investigators JS and CM and researchers SR and JR. From March to December 2010 we collected field data and gathered policy and site documents from each Trust (>200). SR and JR carried out participant observation of shift handovers, review meetings and transfers of care with contributions from NM and KC on one site (n=50 transcripts). SR and JR carried out 86 semi-structured, face-to-face, audiotaped interviews with staff, managers and stakeholders. Interviews with postnatal women (n=58) and partners (n=6) were carried out by SR and JR with contributions from CM and WC. Interviews and field notes were transcribed in full.

We here report only on findings from the women's interviews. Sample size and composition were guided by considerations of project time and resources, estimated to allow for interviews with approximately 60 women; maximum variation (Sandelowski 1995) to include women with a range of socio-demographic characteristics (age, ethnicity and parity) and areas of residence; purposive sampling on each site of some women who had experienced transfer and escalation of care; and criteria of data saturation when interviews were considered sufficient to respond to case study research questions.

In the first strategy for recruitment, midwives telephoned women who had delivered in the previous six months to ask if they were willing to meet with a researcher for an interview about their birth experience. Only women who agreed were approached by the interviewer. Our second strategy was to contact community centres with mother-and-baby groups. Facilitators informed women about the study and asked if any were willing to meet with a researcher waiting in an adjacent space. Women who gave interviews did so voluntarily, so refusal was not an issue.

Thirty-two women were interviewed at home, 26 of them individually and 6 with their partners. Couples were asked to talk to each other about the birth experience with periodic questions from the interviewer. Twenty-six women gave interviews in out-of-home settings, 15 of them individually and 11 in group interviews (four pairs and a trio). Interviews were held in mother-and-baby sessions in children's centres (18), a youth centre (2) and the home of a National Childbirth Trust leader (5), and in a hospital after one woman's clinic appointment. Interview duration was 40 to 80 minutes in women's homes and 20 to 40 minutes in out-of-home settings where women had less time available. Time and group dynamics varied across the sample, but interviewers gave priority overall to creating a tranquil atmosphere for women to narrate their birth experiences and establish their own priorities in doing so. All interviews were in English: two women had limited fluency but they did not require interpreters.

Data analysis

We used a framework approach combining deductive and inductive analysis (Ritchie and Lewis 2003), commencing with definitions of quality and safety (IOM 2001) and amending the initial framework as new themes emerged from the data. Analysis was further guided by discussions with the study's multi-disciplinary Co-Investigators' and Advisory groups.

SR and JR coded all interview and field notes transcripts independently using NVivo8 software. In team meetings we discussed differences of interpretation and developed a consensually-agreed set of analytic categories. In the resulting thematic tree, under the dimension of 'Woman-centred care' (Reid 1997) we created the heading 'User voice' with subheadings including 'Staff response' and 'Users speaking up/not speaking up'. This latter node contained 175 references from 57 sources, making it one of the most frequently referenced categories in the study. A further phase of manual coding produced themes that were discussed in the Birthplace case study report (McCourt *et al.* 2011): partner presence as a facilitator, staff failure to listen, and women's regrets when they were unable to speak up. In a further stage of analysis we tabulated data from all women's interviews under the headings of Safety, Knowledge, Voice and Agency, and Staff Response. This produced a more detailed and comprehensive overview of the content and frequency of speaking up accounts across the study.

FINDINGS

The first result of our analysis was a redefinition of speaking up in the context of maternity services. Studies in other areas of healthcare have alluded to roles taken on by patients such as reporting, informing and vigilance (Egberts *et al.* 1996); asking factual or challenging questions about their treatment (Davis *et al.* 2008); challenging professionals about safety concerns (Entwistle *et al.* 2010); giving practice improvement feedback, questioning and advising practitioners, confronting staff, and attempting to challenge or change care practices (ledema *et al.* 2012).

The most relevant definition for our analysis was that of Lyndon *et al.* (2011) who referred to clinicians speaking up about safety concerns in labour and delivery in terms of assertive communication and 'stating concerns with persistence until there is a clear resolution'. We defined speaking up as *insistent and vehement communication when faced with failure by staff to listen or respond on at least one occasion.* Insistence was the main feature that differentiated speaking up from 'just speaking' and being heard. Levels of vehemence varied depending on the urgency of the situation as perceived by the woman, and this will be illustrated below.

Women who spoke up

Of the 58 women interviewed, 30 reported speaking up in the course of their latest pregnancy or birth. The similarity in numbers of women who spoke up and those who did not was also reflected across socio-demographic groups (Table 1):

Table 1

Postnatal women (n=58) who spoke up and did not speak up in latest pregnancy or birth by age, ethnicity and parity

	Women in sample (n=58)	Women who spoke up (n=30)	Women who did not speak up (n=28)
Age group			
<20	9	4	5
20–29	16	7	9
30–39	31	18	13
≥40	2	1	1
Ethnicity			
White (British, Irish, European)	50	26	24
Black and Minority Ethnic (British, Asian, African, Caribbean, Latin American)	8	4	4
Parity		·	
Primiparous	41	20	21
Multiparous	17	10	7

Women who did not speak up

Women who did not speak up could also have experienced problems in antenatal, intrapartum or postpartum care, but for different reasons they did not insist or communicate vehemently with staff. Of 28 women who did not speak up, 15 considered that professionals had greater knowledge, or opted for a strategy of compliance with clinical authority when complications arose (Abel and Browner 1998; Tanassi 2004; Westfall and Benoit 2008). On the basis of past experiences or their observations on the wards, some women feared that they could be labelled over-demanding if they spoke up.

Four women said they had thought of speaking up but lacked certain resources: time or an opportunity to intervene; clarity of mind when struggling with pain, the effects of anaesthesia, or feeling unwell; information about their condition or treatment; and/or confidence in their own knowledge. Some expressed regret or self-blame for not having been more assertive, as in this case of this woman who had wanted to avoid an episiotomy by remaining vertical in labour as indicated by her community midwife:

I have been thinking quite a lot about, I was almost like, should I have been more vocal about that, should I have made them get [named midwife] in, should I have... because I'm pretty sure they wouldn't have cut, like [named midwife] would have... (...) But obviously in the height of it all you don't... you don't... you can't really think it through. (...) But it all happened so quickly in the end that I lost that window of opportunity. (...) I think it's probably more me and my husband, we should have been more... if I felt that strongly about things I should have waved my birth plan for the moment I got in there. [Postnatal woman 23 Site 1]

The nine remaining women who did not speak up had not needed to do so because they had dialogic communication with staff who listened and responded promptly. Some women commented that the quality and continuity of their care had been exceptional given the constraints on NHS staff time. They gave special credit to professionals who made them feel at ease and did not trivialise their concerns: "... you felt like you could come out with the stupid questions, you know, and you wouldn't

feel silly" [Postnatal woman 23 Site 3]. Even during critical experiences, 'just speaking' in a positive care relationship was sufficient for them to get heard. One teenage mother had a complicated birth with an epidural and ventouse delivery. Although she suffered bruising and severe pain she described her overall experience as good, and she also felt she was given special support because she was young:

Interviewer - Can you tell me how the birth experience went for you?

Woman - Um... well, well... my birth was... um... complicated but it was, it was good. (...) ... it helped how the midwives were with me. They made sure I knew what was going on, they made sure I was comfortable and they listened to me as well and that was important (...)

Interviewer - Did you think as a young parent you were treated differently from other mothers?

Woman - I think if anything I got more support because I was young mum than other mothers would have. I think at [hospital] they do understand that when you are younger that sometimes things can hit you a little harder because like you are still growing emotionally. So, yeah, but, I had the same midwife all the way through my pregnancy. I had like constant support and help. [Postnatal woman 28 Site 2]

Concerns and safety alerts

Previous studies have referred to 'safety concerns' as the topic of speaking up (Lyndon *et al.* 2011; Entwistle *et al.* 2012), but we noted a qualitative difference between expressions of concern and safety alerts. Women tended to raise concerns somewhat hesitantly, especially if they were first-time mothers, feeling that staff might put their worries down to anxiety or inexperience. Nevertheless, some learned in practice how to press for a response:

... you had to be quite insistent, you had to be confident enough to say, well I do need something and I will press that buzzer, and... not be put off if they are... sort of impatient, or short with me. Just stand your ground and say... um... 'I need to... I was meant to have the result of this test and I haven't heard anything, and what's happening?' Or, 'When is my catheter going to be taken out?' Or, you know, that kind of thing. 'What's going on?' [Postnatal woman 17 Site 2]

Safety alerts were characterised by increasing levels of vehemence when women felt the need for an immediate response from staff, as in this case:

I panicked like mad, and um, they [midwives] were still insistent that they weren't going to get any more [Entonox], so I turned round and I said, 'Right, I want you to call the ambulance then, because I'm not staying here. I'm not going to go through this (...) I was really mad. I remember being exceptionally mad. (...) I just felt like I was being ignored. (...) I felt like I was screaming and no one was listening. I felt like my wishes were being completely disregarded, at that point. [Postnatal woman 32 Site 3]

Expressions of concern and safety alerts sounded different, but they could be conceptualised as poles on a continuum. If a woman's concern remained unheard, her condition or that of her baby might deteriorate leading to a situation she felt to be urgent. If response was further delayed, the woman could abandon scruples about challenging staff and make vehement calls for help. In the case just cited, the woman passed from repeated requests for pain relief at home to an angry demand for transfer because she felt profoundly unsafe. Even when speaking up proved effective

and physiological harm did not ensue, the emotional pressure women endured could negatively mark their overall experience of care.

Topics of women's safety alerts

Fourteen of the 58 women reported speaking up in situations they felt to be urgent. They came from all sites and had varied characteristics in terms of age, ethnicity and parity. Box 1 provides examples of safety alerts about requests for attendance in labour, signs of risk in labour, and neonatal pathologies:

Box 1 Examples of women's safety alerts

Raising the alert about meconium-stained liquor: "... when you have this colour..."

Partner - ... first time she find it, the... is water colour little change. Then I call. (...)

Woman - I say, 'It's like green, or something like this.' (...)

Interviewer - And what did the midwife say?

Woman - Waiting for me, I'm coming nine-thirty (...) this for us strange because (...) all what I read, this is when you have this colour you must straightaway go to hospital. (...) and [midwife] says, 'No, waiting, like four, after four hours I am coming.' And we scared, oh my God, what? Four hours? This is too long. (...) And she coming, she says, 'Yeah, we go to hospital.' [Postnatal couple 19 Site 2]

Warning of baby's imminent arrival: "I know my body..."

... they kept telling me that I was in early labour, to go home and come back the next day. (...) And [midwife] just said something like, 'I think you're only three or four centimetres,' and I goes, 'Well hadn't you better check because I'm telling you... this little 'un's coming out and she's coming out now.' 'No she's not, you're panicking, you don't know what you're on about.' I says, 'Look, I've already had two, and I know my body better than you know my body. And I'm telling you this baby's coming out in the next five minutes.' 'Well just bear down and breathe your way through it.' And I thought, sausages to this. I pushed, and [baby] came flying out. She only just caught her hitting the end of the bed. [Postnatal woman 31 Site 3]

Insisting about baby's respiratory symptoms: "I knew there was something not right..."

... being a first-time mum I knew there was something not right but I didn't want to, you know, be one of them ones to sort of just run straight up to A&E. So I thought I'd ring [telephone service], (...) I put the phone up to [baby], you could hear her rattling, and her breathing was shallow, (...) like she was gasping for breath, really badly. (...) and [nurse] said, 'It just sounds like she's got the snuffles.' I said, 'But it's not.' Obviously I'd explained the whole... all her symptoms. (...) Well [GP] rung me back and he basically just said, 'She's got the snuffles, there's nothing wrong with her. (...) and basically it got to half six in the morning and we just said, 'Look, something's not right, we need to go to the hospital.' (...) So we got to A&E and they were amazing, they just literally took [baby] straightaway and they, they checked her and they said, 'Look, she needs to have a lumbar puncture.' (...) I think it took about 36 hours to find out it was actually pneumonia (...) she was on the High Dependency for 24 hours and then we got moved to a ward for five days, and she was on antibiotics... [Postnatal woman 39 Site 2]

Facilitating factors for speaking up

Women who spoke up were socio-demographically diverse, but there was some commonality in the factors that facilitated their ability to call for staff's attention. One already mentioned was the vehemence that came from the sheer urgency of women's feelings of being at risk. Another was the confidence some women acquired from information found in online searches: "Really, all in internet, I sit, I read all night, all day..." [Postnatal woman 19 Site 2].

A key facilitator, highlighted by 13 of the 14 women who spoke up about urgent safety issues, was the presence of a partner or relative. The roles of these supporters included the following:

- Encouraging the woman, backing up her requests
- Speaking up on her behalf, for example if she had little English
- Becoming the main speaker if the woman was focused on labour, in pain, weakened, or unwell
- Taking on critical caring responsibilities, including delivery of a baby when staff failed to attend in time.

The examples in Box 2 convey the importance women gave to this support, but also the augmented tensions in labour and birth when all those involved felt unsafe, fearful or angry:

Box 2 Examples of partners' and relatives' support

Becoming the main speaker: "we are entitled to a home birth."

... they said, 'Oh, there's no midwife, you're going to have to come in.' And [husband] said, 'No, [X]'s said she's having a home birth, we've been told by our midwife we are entitled to a home birth, you need to send somebody out.' Um... and er... she [hospital operator] said, 'Oh well, call us back in half an hour, or...' you know. (...) But I know when [husband] then phoned again, they said, 'We haven't got anybody.' He's like, 'No. You're sending somebody out.' [Postnatal woman 13 Site 1]

Backing up the woman's demand for explanation: "My sister had to tell them..."

... after um they gave me the epidural and they pressed the crash button (...) so many people were sticking needles inside of me and I was really scared and no one could explain to me what was going on. My sister had to tell them all to stop that, let them basically explain to me cause I was telling them no one should touch me cause I didn't know what was going, because I was really scared and I was like what is going on with the baby and what is going on with me cause by that time I was so numb from basically from my neck all the way down and I didn't know what was going on. [Postnatal woman 27 Site 2]

Taking on critical caring responsibilities: "we just delivered a baby."

So [partner] called the, I think the, yeah, called the hospital as well, and er... and he said, 'Yeah, we just delivered a baby.' And um... and they were like, 'Yeah, what's the due date?' He's like, 'Look, due date? The baby's here, we just delivered it.' (...) ... and then they told him to, yeah, just gave him a little bit instructions and told him to call the ambulance as well. So he was on the phone like one with the ambulance and one with the midwife. And they told him, yeah, he should, we should wrap him in a towel and put it on my chest. But I wasn't really happy, he looked at me like, 'You have to put him on your chest,' and I was like, 'No.' He was like, '[X], I'm not joking!' And I was like, 'No, just don't really...' And he's like, '[X], we put him on your chest now.' [Postnatal woman 20 Site 2]

When women were unaccompanied they seemed to have less success in standing their ground. One woman spoke up successfully with her partner's support about meconium-stained waters (see Box 1), but when he was not with her postnatally she felt unable to communicate with staff about difficulties with breastfeeding:

"Is a lot doctor, a lot midwife, but I feel like I'm alone, in one island, and nobody... can help me (...) but after when coming, er... X [partner], X helped me. [Postnatal woman 19 Site 2]

Only one of the women who reported speaking up about a safety issue she considered urgent did not have a partner or relative present. Despite her insistence, she was unable to obtain the presence of a midwife to attend her planned home birth. She had to transfer in, her cervix was found to be 7 cm dilated, and her waters were broken. The baby was born suddenly and she could not get off the bed quickly enough for the delivery:

I had a second degree tear because it was so quick. (...) I lost a lot of blood, I nearly had to stay in. I nearly had to go to surgery for stitches. (...) They [staff] said, 'We had midwives to come out.' They weren't convinced that I was that far gone. They listen - even when you talk to them on the phone - to how you're breathing and talking. I'm one of those people who don't show it. (Postnatal woman 5 Site 1)

This woman was 34, she had given birth before, and she was an active NCT member: all characteristics denoting experience, knowledge and agency that could have favoured her negotiation with staff. Her suggested recommendation to the service was "Listen to the second time mums more". However, our findings suggest that whatever women's characteristics, they were more likely to be heard if they had a partner or relative present to reinforce their request. This potential was illustrated by one woman whose partner managed to obtain the presence of a midwife to attend their planned home birth, although the service was refused to others that night on the grounds of staff shortages (a situation corroborated in other interviews). She attributed their success to stubborn personalities and also to the influence of her father's legal background: "... my dad's brought us up that, you know (...) these are your rights, you know your rights, and that's that" [Postnatal woman 13 Site 1].

Staff failure to listen

Speaking up gave no guarantee of being heard or responded to. Women described the following types of staff behaviour that made speaking up both difficult and necessary:

- Ignoring requests or dismissing safety alerts
- Delaying or withholding information, care or support
- Disbelieving the woman's account of stage in labour or symptoms in self or baby
- Responding brusquely or rudely to requests for help
- Refusing labouring women admission or sending them home feeling unsafe
- Refusing presence of midwife to attend a planned home birth

Box 3 illustrates women's accounts of deterioration in their condition or harm that ensued in labour or postnatally after their safety alerts went unheard:

Box 3 Examples of staff failure to listen and respond

Woman's alert about waters breaking: "I did tell them but they didn't believe me..."

I knew most of my waters went and ... (...) they [midwives] just said "no your waters is fine" and I was sort of saying "yes some (of) my waters have gone, I told you", what could I do? (...) I was actually trying for a normal, I was trying for a VBAC, which is a vaginal birth after a C-section. (...) I did tell them but they didn't believe me and they said "Oh I can't feel no leakage or nothing," but when they checked half my waters was gone and only a little bit was left and cause I was there for like a few hours, around like 6 to 7 hours and they said it was not safe to stay like that no more, so and they said I had to go for an emergency C-section, so that was it, I had no choice. [Postnatal woman 26 Site 2]

Partner's warning about risk of bruising: "... they didn't listen. They used that hand anyway..."

I was put on a drip during labour because of my energy levels. (...) When they came to put the drip in, my husband told them to use the other hand because that hand bruises — I'm not very generous with my veins — but they didn't listen. They used that hand anyway and I wasn't in a position to argue. I got bruises all up my arm. [Postnatal woman 48 Site 4]

Woman's insistence about vulval haematoma: "I kept on asking..."

I started to feel loads of pressure (...) like I had a heart beat down here, here and so I thought is it [haematoma] forming again? (...) every little thing I was asking the midwives I was really concerned. I really didn't want to go back or get any worse so I kept on asking and they were like "It is fine, it is fine." (...) I kept on thinking "is it normal. Is it normal?" To me I didn't know... to the doctors it was (...). They're like "Yeah, It is normal." But then when it got bigger and bigger everyone I showed it to, the midwives (...) said "Oh my God I have never seen anything like that in my life. (...) It was only after my auntie and my mum complained to them that they started to give me antibiotics and everything. [Postnatal woman 30 Site 2]

When staff *did* take the time to listen and explain, even after a traumatic event there was the potential for women to have more positive feelings about their overall experience. One woman had an infection and fever during labour and an emergency Caesarean when the fetal heart rate dropped. She was upset at not seeing her baby at birth because he was rushed to intensive care. The next day she spoke to a midwife who gave her an explanation, and the woman ended her interview by expressing some satisfaction with the care she received:

... we [woman and midwife] spoke about it the next day because he was still in special care, and I was kind of like upset that the whole thing had gone that way. (...) my midwife at the time, she said, (...) "when they cut you, um, the baby's head wasn't really down in your pelvis", so you know, I could have gone the full ten centimetres dilation and had to have an emergency Caesarean anyway. And the cord was all round his neck and... there was multiple things that, you know. So... I've kind of got over it. (...) you know, it's fine and he's here and... I was quite happy with the care that I had. [Postnatal woman 25 Site 3]

Speaking up and being heard: women's perspectives

Box 4 summarises findings from women's interviews on factors that influenced their ability to speak up and staff readiness to respond:

Box 4
Barriers and facilitators to speaking up and staff response from the perspective of women interviewees

	Women's ability to speak up	Staff readiness to respond
Barriers	 First-time mothers' feelings of inexperience and doubts about validity of their concerns Being unaccompanied Effects of pain, anaesthesia, feeling unwell Lack of information about condition or 	 Staff failure to listen Brusque or impatient staff behaviour Staff disbelief or disregard for safety alerts
	treatment	 Lack of staff time in busy services
Facilitators	 Urgency of a woman's feeling of being at risk Presence of a partner or relative Previous birth experience and confidence in own knowledge and intuition Information about rights and entitlement 	 Presence of staff prepared to listen Presence of a known midwife Continuity of care Support programmes for young and vulnerable women

In a few cases (n=9), women did not feel the need to speak up at all during their latest pregnancy or birth because staff were already listening. When some of these women experienced complications, transfer and escalation of care, 'just speaking' was sufficient to obtain a response, and they were not subjected to the double burden of feeling unsafe and making insistent calls for help.

DISCUSSION

Many patient involvement in safety initiatives have been based on a deficit model which supposes that patients need to be given specific facts and stimuli in order to engage in safety-promoting behaviours (Peat *et al.* 2010; Schwappach 2010). In recent years it has been argued that patients in acute and general health care settings have the potential to act as safety buffers by voicing concerns and pre-empting failures in care (Reason 2000; ledema *et al.* 2012; Scott *et al.* 2012). Our analysis shows that women using maternity services also demonstrate this ability. Guided by experiential and embodied knowledge (Abel and Browner 1998), as well as online information which is being increasingly consulted, they can raise alerts about safety issues before professionals are aware there is a problem. The frequency in our data of women's speaking up accounts suggests that this practice may be common, potentially effective, and worth encouraging.

Nevertheless, according to our definition, the *need* to speak up is associated with at least one precedent of being unheard or ignored. Several interviewees rationalised staff failure to listen in terms of overload in NHS services. The sites studied, despite being located in Trusts assessed as high-achieving, may sometimes have functioned in the "unsafe zone" (Vaughan 1999; Amalberti *et al.* 2006) where "staff may not have adequate resources to prevent errors and mitigate safety threats" (Jeffs *et al.* 2009:76). The failure to listen so frequently reported in our study may form part of an institutional culture that normalises reduced attention to women's calls for help.

Former studies have found that more educated/better-off/white women may be more able to stand up for themselves in maternity services than women from disadvantaged social groups. However, they also noted the compensatory effects of programmes supporting women in situations of vulnerability (Magee and Askham 2008; Raleigh *et al.* 2010; Redshaw and Heikkila 2010). In our study, women with varied socio-demographic characteristics were able to speak up. The potential social disadvantage of some teenage mothers was apparently mitigated by the care they received from caseloading midwives providing continuity of care.

A facilitating factor mentioned by many women who spoke up was the presence of a partner or relative. There is ambivalence in this finding because the empowering effect of an ally's presence had its counterpart in the relative insufficiency of a woman's lone voice to get heard, however well-informed or experienced she was. This begs the questions: should maternity service users have to depend to this degree on the presence of a companion to negotiate safe care? Are unaccompanied women more exposed to risk?

CONCLUSIONS AND FUTURE DIRECTIONS

In response to the question in our title, we conclude that many women *are* speaking up, but this is not enough: staff need to listen and respond. Staff awareness needs to be raised about the value of women's concerns about situations they feel to be unsafe, and the need for case-by-case assessment before dismissing their safety alerts. Efforts should be made to improve communication and staff response, with special attention to women in situations that make speaking up difficult.

These transformations are notoriously difficult to achieve, and they often require changes in institutional culture and practice. UK examples of such interventions include the Real Time Patient Feedback initiative in Royal Devon and Exeter NHS Foundation Trust (Larsen *et al.* 2011), and the Patient Toolkit and patient incident reporting strategies currently being developed by the Yorkshire Quality and Safety Research Group (Lawton and Armitage 2012). U.S. examples include The Joint Commission's "Speak Up" campaign, and the "Condition H" help line for patient-activated rapid response calls in the University of Pittsburgh Medical Center. Examples from Australia include the Clinical Excellence Commission's "Partnering with Patients" programme, and the REACH Toolkit (ACSQHC 2011) which incorporates an evidence-based literature synthesis on Patient and Family-Activated Rapid Response. Research is needed in maternity services, as well as acute and general health care, on the effectiveness of organisation-focused interventions that aim to create enabling conditions for users' contributions to their own safety.

LIMITATIONS AND STRENGTHS

In this paper we only report on findings from women's interviews; perspectives from providers, researcher observations and other data sources are not presented here. This qualitative study was not designed to measure prevalence, and numerical distribution of cases can only provide approximate indications of frequency. Another limitation is that the Birthplace sampling strategy targeted some women on each site who had experienced complications and transfer, and the resulting sample cannot be taken as representative of the wider population of maternity service users.

Strengths of the study include the use of qualitative methods which allowed in-depth investigation of women's narratives about their experiences of maternity care; the spontaneous mention of speaking up by a considerable number of women although questions on the topic were not included in the interview schedule; and the large number of participants with a range of socio-demographic characteristics from differently-configured sites in four geographical areas, thus increasing potential relevance of the findings for maternity services across England.

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