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Supporting parents through stillbirth: a qualitative study exploring the views of health professionals and health care staff in three hospitals in England

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Short running title: Supporting parents through stillbirth

Investigating the views of hospital based health professionals and health care staff in supporting parents through stillbirth: a qualitative pilot study.

• Objective: To investigate the views of a range of hospital based health professionals and health care staff in the management of stillbirth

• Design: A qualitative pilot study informed by grounded theory

• Setting: Three hospital trusts based in the North East of England

• Population or Sample: 21 consultant obstetricians, 3 trainees (including 1 senior trainee), 29 midwives, 3 midwife sonographers and 4 chaplains.

• Methods: Focus groups and semi-structured interviews

• Main Outcome Measures: To clarify experiences and views of hospital based health professionals and health care staff. To highlight potential gaps in training needs for these staff groups.

• Results: Two different approaches in stillbirth management could be detected in our study. One approach emphasised the existing evidence-base and patient directed choice whilst the other emphasised tradition and profession-directed care. These differences were particularly apparent in choices over mode of delivery, and the location of women as well as the time interval between diagnosis and delivery.

• Conclusions: Disagreement exists among clinicians regarding best practice in managing two important decisions in stillbirth: mode of delivery and location of women and the time interval between diagnosis and delivery. High quality evidence is needed regarding the long term impact, including the psychological and emotional sequelae, of these two key decisions in stillbirth. Such high quality evidence will enable clinicians to provide women with fully informed and meaningful choices.

• Keywords: Evidence, tradition, stillbirth, health professionals, health care staff, care, patient choice

Introduction

Stillbirth is legally defined in the UK as “A baby delivered after 24 weeks 0 days without signs of life”. n 2015 the stillbirth rate was 3.87 per 1,000 total births, a fall from 4.20 in 2013. Despite this reduction UK stillbirth rates remain high compared to similar European countries, with significant variation across the UK that is not solely explained by important factors such as poverty, mother’s age, multiple birth and ethnicity.[[1]](#endnote-1)

Previous research investigating patients’ experiences around stillbirth has shown that mothers and their families are profoundly affected by staff attitudes and behaviour[[2]](#endnote-2) [[3]](#endnote-3) and often suffer social stigma in the clinical setting and beyond as a result of stillbirth[[4]](#endnote-4)[[5]](#endnote-5)[[6]](#endnote-6). Further, important associations have been demonstrated between mothers’ mental health outcomes and their perceptions of support and information from health care professionals, as well as between mental health outcomes and opportunities for memory making and sharing following stillbirth[[7]](#endnote-7) [[8]](#endnote-8).

The literature also shows that health care professionals and health care staff experience distress when managing stillbirth[[9]](#endnote-9) [[10]](#endnote-10) [[11]](#endnote-11)and often feel unprepared because of a lack of adequate training and support [[12]](#endnote-12) [[13]](#endnote-13) [[14]](#endnote-14). Wallbank and Robertson[[15]](#endnote-15) found that staff distress in the event of stillbirth and neonatal death was predicted by a negative appraisal of care given to the family, staff perception of support outside of work and a lack of supervision support at work, among other factors. Kelley and Trinidad’s[[16]](#endnote-16) US study found that doctors and consultants often discussed future possibilities (i.e. the next baby) long before parents were able to consider it and focused upon causes of the stillbirth rather than emotional support. They concluded that medical professionals can play an important role in reducing the stigma of stillbirth.

This study focused on the challenges faced by hospital based health professionals and health care staff in managing stillbirth and was conducted in three hospitals based in the North East of England; Sunderland Royal Hospital, Gateshead Queen Elizabeth Hospital and South Tyneside Hospital. The study’s design was informed by grounded theory, allowing for the emergence of themes not currently identified in the literature.

Methods

Grounded theory[[17]](#endnote-17), thematic content analysis[[18]](#endnote-18) and constant comparison[[19]](#endnote-19) [[20]](#endnote-20)were used to generate qualitative data. Grounded theory allows themes to ‘emerge’ from the data. Alongside grounded theory the constant comparative method was used so that data were analysed from the beginning of the study, so that newly identified important themes could be incorporated into subsequent data collection. This enabled the development of the most salient points from the perspectives of participants.

*Recruitment*

Expressions of interest to participate in this study were sought by the study’s Research Midwife who was also responsible for recruitment to the focus groups via the Principal Investigator (PI) at each hospital site. The study’s lead researcher subsequently liaised with each site’s PI. Six focus groups were conducted in three hospital trusts in North East England, one at site A (n=16), three at site B (n=26) and two at site C (n=18).

*Inclusion/Exclusion criteria*

Recruitment was restricted to key groups of health professionals and health care staff considered to be ‘front line staff’ in managing stillbirth.

*Sample*

A purposive sampling frame was used, within which self selection occurred. A total of 60 health professionals and health care staff participated in the study; 21 consultant obstetricians, 3 trainees (including 1 senior trainee), 29 midwives, 3 midwife sonographers and 4 chaplains. Of these, one consultant obstetrician and one midwife sonographer who could not attend any of the focus groups were interviewed..

*Focus groups*

Early focus groups followed a brief topic guide that began with an open ended, core question: **‘**What experiences have you had in managing stillbirth?’ After some discussion subsequent questions became more focused. Where focus group discussions faltered topics suggested by the existing literature were raised: these included: training, the professional and personal impact on participants of stillbirth management, supportive interventions and needed changes to practice.

Later focus groups and the two interviews came to focus increasingly on protocols, a lack of high quality evidence regarding stillbirth management, a reliance on traditional practices and the appropriateness of offering women choice in mode of delivery and going home or remaining in hospital for 48 hours before delivery.

All focus groups were led by the same researcher with a research assistant participating in one focus group. Focus groups lasted between 40 minutes and 2 hours and took place before rounds, during a lunch break or as part of a regular research day. Two semi-structured interviews lasting 30-45 minutes were conducted with health professionals who were unable to attend the focus groups.

Two of the focus groups were comprised of a single profession, one of chaplains and another of midwives (both Site B). The remaining four focus groups were mixed and included one senior registrar, consultant obstetricians, junior doctors, midwives and midwife sonographers. Overall, the mixed focus groups generated the most animated discussions and, possibly for this reason, were the most informative.

Data from the focus groups were audio recorded and transcribed by a third party. Data from the interviews were audio recorded and notes were taken from the interview recordings and used to supplement, confirm or critique data collected from the focus groups. Both interviews were conducted after the focus groups had been completed. Focus group transcripts were analysed using thematic content analysis by four researchers, first individually and then as a group. Key themes were identified through open coding and relationships between themes via axial coding.

### *Ethics*

Ethical approval for the study was granted by the participating HE institution Research Ethics Committee (UREC), application number 217 on 24th June 2014. UREC was sent updated information at an interim point in the study that reflected the modified study design and materials. Approval for these modifications was received from UREC on June 25th 2015.

Results

Two principal themes emerged from the focus groups and interviews. These were; a lack of rigorous, high quality scientific evidence on the most effective way to manage stillbirth in terms of the long term physical, mental and emotional well-being of mothers, their partners and families; and the ability of mothers (and their partners) to make the right decisions (for themselves) when faced with an emotive, stressful and time pressured life event such as stillbirth. Appealing to tradition and practitioner experience was seen as the necessary consequence of both a lack of evidence and the perceived inability of parents to make appropriate choices.

These themes emerged during discussions of patient choice in two key areas: caesarean section versus normal (vaginal) delivery (Figure 2) and going home or remaining in hospital for 48 hours before delivery (Figure 3). Those health professionals emphasising the need for patient choice tended to cite the research evidence base, even whilst acknowledging its inadequacy, whereas those emphasising profession directed care tended to rely on tradition and local contexts. These two approaches to stillbirth were clustered around different sets of attitudes and values, as shown in Figure 1. Importantly these clusters cut across professional boundaries.

*Science versus tradition/local practices*

A lack of high quality evidence in stillbirth management, generally perceived as Randomised Controlled Trials, was seen as particularly problematic, whilst simultaneously there was an acknowledgement that generating such evidence was difficult, if not impossible. This created an obstacle to changes in practice which, in turn, led to a reliance on tradition. A lack of guidance in managing subsequent pregnancies after stillbirth was particularly highlighted.

However, some health professionals claimed that even high quality evidence would not change their practice because their approach was individualised to the needs of each mother. Follow- up with individual patients who had experienced stillbirth was suggested as more beneficial than research evidence, but many reported that they never saw patients who had experienced stillbirth again:

Evidence regarding reducing the stillbirth rate also met with some scepticism. Here too the evidence was not considered universally applicable and not directly transferable to the North East of England, with its particular demographic and cultural characteristics:

|  |  |
| --- | --- |
| Science/evidence | Tradition/localised practices |
| *We only think we can change if we’ve got top level evidence…it’s impossible to generate that kind of information…So we’re a hostage to both science and tradition. And a lot of what we do at the minute is us being a hostage to tradition* (Consultant, Site B) | *There isn’t really a guideline or any research that would help for me personally. I think it’s just so individual and it’s so rare that you have to do it. I just think you’ve got to take your lead from the woman. It’s not a one box fits all scenario* (Midwife, Site C) |
| *People will have done small bits of research everywhere then one clever person, you know, puts it all together.. [and]...randomised controlled trials ... that is the evidence* (Consultant Site C)  *I think the default position for anyone who’s had a stillbirth is exactly the same. Whatever they show externally, their emotional response is exactly the same through any culture, whether they’ve had kids before or whatever. You’ll see people being outwardly upset, other people being quiet, you see other people being angry and some people being accepting. But actually, it’s all a front and I think all the stuff behind is exactly the same from one woman to the next* (Consultant, Site B) | *The reason why the stillbirth rate is lower in Scandinavian countries. [than the north east].. is the level of female education there...* *Most women there have been to university. And so they take better care of themselves when they’re pregnant, they don’t drink and smoke, they attend all the appointments* (Consultant, Site C) |

Figure 1

*Mode of delivery*

The reported lack of locally applicable, high quality evidence and a subsequent reliance on tradition led to patients rarely being given a choice over mode of delivery.. Despite claims of individualised care, it seemed that, on this issue women were directed down a standard pathway and given the impression that there was only one option open to them, despite the acknowledgement that women did often request a caesarean section in stillbirth.

Most consultant obstetricians and all midwives in this study considered normal delivery to be best in stillbirth. Reasons included:: a lack of authority on the part of midwives to offer a caesarean section, a mother’s choice not being sufficient justification, potential long term physical side effects such as scarring and damage to the uterus impacting on future pregnancies, the risks of major surgery and cost. Of further note was the lack of an important justification for caesarean section in stillbirth, the welfare of the baby. In this discussion clinical safety was generally prioritised over mental and emotional well-being:

Indeed, those health professionals advocating normal delivery in stillbirth saw this as psychologically beneficial for mothers. It was reported that women who insisted on a caesarean section later regretted it, but again, a lack of high quality evidence on this issue was seen as problematic..Relatedly, health professionals disagreed whether women were able to make informed decisions in stillbirth, a stressful and emotionally charged event.

|  |  |
| --- | --- |
| Caesarean section Normal delivery | |
| Patient Choice | Professional Guidance |
| *When was the last time someone offered someone a caesarean section for a stillbirth? There’s national guidance that says we should...The RCOG has said that this is something that should be considered rather than inducing someone...we conveyor belt them* (Consultant, Site B)  *Generally, [there is] great reluctance to do a C Section for a stillbirth. Even if the labour is not progressing in the way it should be. We are going for that more, avoiding operations but not perhaps considering ...the entire picture of how the experience is for her* (Senior Trainee, Site B)  **Facilitato**r: *Do women often say ‘Can I have a caesarean section’?*  **Midwife Sonographer**: *Yes* (Site B) | *usually we do caesarean sections for the sake of the baby most of the time ...But in this case, the baby is dead...so...you need to know why she is asking for a caesarean section. I think there is one ...condition ...in advanced pregnancy. Maybe that’s applicable. But to be honest, we don’t offer it* (Consultant, Site C)  *if they did have a section... [the baby’s] been taken away.....is there any bonding [with the process of caesarean section]...?* (Midwife Sonographer, Site B) |

Figure 2

*Going home for 48 hours before delivery*

The distress reportedly expressed by women at the thought of being sent home for 48 hours before delivery was perceived by some health professionals as an initial shock reaction and one that, once staff had ‘explained’ the process and given women time, was reversed. However, the responsibility for suggesting an alternative, i.e. staying in hospital, seemed to rest with the woman. The viewpoint that going home was ‘normal’, appeared based upon clinical, rather than emotional and psychological, considerations. Again, the ability of women to make informed choices was questioned, despite the acknowledgement that women often requested information about the process from the outset.

|  |  |
| --- | --- |
| *Location/duration between diagnosis and delivery* | |
| *Choice* | *Guidance* |
| *That [viewpoint] is a classic, classic paternalistic response which we fight against constantly in medicine and then we talk about things like consent, you know, do they really want to know? And I think we do choose for them a lot because of that reason that we think they’re not capable of making decisions. Well I tell you, they are. They are capable* (Consultant, Site B)  *Really, do we give them that option to stay?* (Consultant)  *I think it’s implied that the normal process is to go home*(Junior Doctor)  **...** *it’s a default position. And actually how would they know that you could do that [go home] unless someone actually … says* (Consultant)(Focus group discussion, Site B) | *I think at that point that you’ve told them, do they know what they want at that point? Do you think that they are thinking straight at that point?* (Midwife, Site B)  *...experience has taught us that people don’t always make the right choices where there’s a lot of emotion* (Consultant, Site C)  *You get [from mothers] ...‘why would you send me home? This is horrendous.’ And then they want to go. So it’s just that initial shock and thinking that everything will happen right now* (Consultant, Site A)  *Unless they’re particularly unwell with it....and showing any clinical signs and symptoms... invariably, a good ninety nine percent of the time, they are sent home to come back* (Midwife, Site B). |

*Figure 3*

*Discussion*

Our study highlighted two approaches in managing stillbirth. These approaches can be seen as two discourses; that is, two ways of thinking and acting in stillbirth. One discourse was informed by tradition and local contexts and focused on normalisation and professional guidance. Some health professionals within this discourse considered stillbirth to be ‘so rare...a non- event’ (Consultant, Site C) and that trial based evidence was considered inapplicable to local contexts or to the management of individual cases. Stillbirth is in fact considered statistically ‘common’[[21]](#endnote-21) The other discourse was informed by scientific research evidence and focused on autonomy patient choice. Each discourse centred round a different set of attitudes and values in relation to the availability and desirability of scientific research evidence and the ability of women to make informed choices in an emotionally charged and stressful situation such as stillbirth..These discourses were not profession specific and are summarised in Figure 4 below.

|  |  |
| --- | --- |
| Discourse of science | Discourse of tradition |
| * High quality evidence needed * Universalising discourse- womens’ emotions are the same * Women are rational and can make the right choices * Women should be given the choice over mode of delivery and location/interval between diagnosis and delivery * Emotional/psychological well-being * Autonomy /individual/ personal responsibility discourse | * High quality evidence would not change practice * Established practices/local contexts * Women are emotional and can’t make the right choices * Normal delivery should be encouraged * Going home for 48 hours is ‘normal’ * Clinical safety * Normalising/moral discourse/ women being saved (from themselves) |

*Figure 4*

Tension between evidence and tradition was particularly evident around patient choice regarding mode of delivery. Clinical objections to individual choice in mode of delivery centred on the issues of the physical (clinical) risk to the mother in caesarean section, both immediately and in subsequent pregnancies, juxtaposed to the non- risk to the foetus. Some health professionals claimed the physical risks of caesarean section were over stated whilst others acknowledged these had to be balanced with the potential mental and emotional trauma experienced by the mother (and her partner) in delivering normally in stillbirth, for which it was acknowledged there is less robust evidence. . Our finding that concerns over the longer term clinical and safety implications of caesarean section were not profession specific have been reported by others[[22]](#endnote-22). Such concerns are supported by studies showing that caesarean section is associated with a rise in the rate of mortality/morbidity[[23]](#endnote-23) [[24]](#endnote-24) [[25]](#endnote-25)and that the incidence of uterine rupture for women with or without a previous caesarean section is 11 and 0.3 per 10,000 maternities, respectively[[26]](#endnote-26). Nevertheless, in the U.K. the RCOG states that a caesarean section might be appropriate (in both live and stillbirth) because of 'maternal condition' and that a woman might request it. Increased specialist availability has been recommended to ‘service the elective caesarean commitment’ [[27]](#endnote-27) [[28]](#endnote-28) [[29]](#endnote-29) [[30]](#endnote-30). RCOG guidance instructs health professionals to seek to understand the woman’s thoughts and wishes ‘without trying to shape them’ citing a study of 808 families who had experienced an intrauterine death (IUD) which revealed that decisions about care varied widely [[31]](#endnote-31). Relational rather than standardised care has been shown to be most appropriate in stillbirth[[32]](#endnote-32)

Similarly, the practice of sending mothers home for 48 hours before delivery or for the length of this interval appeared to be informed by tradition and hospital processes rather than by research evidence. It was reported that in most instances mothers were rarely offered a choice. This issue was also closely related to the perceived ability of women to make appropriate decisions for themselves in stillbirth. Comparable research on the granting of intra partum consent in research trials indicates that women are able to make appropriate decisions for themselves and their partners in challenging situations[[33]](#endnote-33) Shared decision making (SDM) in stillbirth is encouraged by RCOG and Sands, whilst persuasion is discouraged[[34]](#endnote-34) [[35]](#endnote-35)Decision making tools are available though they may prove less useful in time pressured contexts[[36]](#endnote-36) [[37]](#endnote-37); [[38]](#endnote-38)Many parents want to know their options in stillbirth in order to make their own choices [[39]](#endnote-39)Our previous research showed that women sought high degrees of guidance in some decisions, for example around memory making[[40]](#endnote-40) Findings elsewhere suggest that both the desire and ability to make an informed choice may vary with the decision point within maternity care and between different women[[41]](#endnote-41) as well as with the preparedness of the patient and the clinical context[[42]](#endnote-42)

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*Strengths and Limitations*

The strength of this study is its exploratory, grounded theory design and the breadth of staff roles included. Issues of concern to health professionals and other health staff were allowed to emerge. Key issues were investigated in depth, enabling an understanding of the rationale for practices around stillbirth including the challenges faced by staff. The same researcher conducted all focus groups and interviews therefore ensuring some consistency in data gathering and interpersonal style.

The study was limited in that it involved three hospital trusts in the North East of England which is a socioeconomically deprived area. The study’s findings may not be generalisable to the rest of the UK or to other national contexts.

*Conclusion*

The existence of two discourses requires further investigation High quality evidence is needed to determine the psycho-emotional implications vis a vis clinical sequelae of caesarean section in stillbirth., Effective implementation of any such evidence needs to consider two potentially competing discourses in medicine. Sensitivity is required on the part of health professionals as, whilst overt paternalism is actively discouraged in contemporary medical ethics,[[43]](#endnote-43)[[44]](#endnote-44) stillbirth may share with other areas of medicine the need for a blended approach where patients seek more guided direction from health workers, whilst still aiming to make final choices themselves[[45]](#endnote-45).

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Disclosure of Interests

There are no conflicts of interest reported.

Contributions of authors were as follows:

Dr Lyn Brierley-Jones contributed to the design of the study, project management, data collection and analysis and led the writing of the paper.

Dr Rosalind Crawley contributed to the design of the study, data analysis and writing the paper.

Ms Emma Jones contributed to data collection, data analysis and writing the paper.

Dr Isabel Gordon contributed to data analysis and writing the paper.

Ms Jo Knight contributed to participant recruitment, project management and writing the paper

Mr Kim Hinshaw contributed to the design of the study, project management and writing the paper.

Ethical approval for the study was granted by the participating HE institution Research Ethics Committee (UREC), application number 217 on 24th June 2014. UREC was sent updated information at an interim point in the study that reflected the modified study design and materials. Approval for these modifications was received from UREC on June 25th 2015.

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