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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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ABSTRACT

Objective: To investigate the views of a range of hospital based health professionals and health care staff involved in the management of stillbirth.
Study design: A qualitative pilot study informed by grounded theory conducted in three hospital trusts in the North East of England. In total, 21 consultant obstetricians, 3 trainees (including 1 senior trainee), 29 midwives, 3 midwife sonographers and 4 chaplains took part in six focus groups and two semi-structured interviews.
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 of an IUD and delivery. The existence of these two approaches was underscored by a lack of high quality evidence.
Conclusion: Robust, high quality evidence is needed regarding the longer term psychological and emotional sequelae of different modes of delivery and varying time intervals and locations of women between diagnosis and delivery in stillbirth. If the competing discourses demonstrated here are found elsewhere then such need to be considered in any future policy development, evidence implementation and training programmes.

Introduction

Stillbirth is legally defined in the UK as a baby delivered after 24 weeks 0 days gestation without signs of life. In 2015 the stillbirth rate in the U.K. was 3.87 per 1000 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].

Previous research has shown that women and their families are profoundly affected by staff attitudes and behaviour in stillbirth [2,3] and often suffer social stigma in the clinical setting and beyond [4–6]. Important associations have been demonstrated between women's 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 [7,8].

The literature also shows that health care professionals and health care staff experience distress when managing stillbirth [9–11] and often feel unprepared due to a lack of adequate training and support [12–14]. Wallbank and Robertson [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 US study [16] found that doctors and consultants often discussed future possibilities with parents (i.e. the next baby) long before they

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were able to consider it and focused upon causes of the stillbirth rather than emotional support.

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 in the North East of England.

Materials and Methods

The study's design was informed by grounded theory, allowing for the emergence of themes not currently identified in the literature. Grounded theory [17]. Alongside grounded theory thematic content analysis [18] and the constant comparative method were used [19,20]. Constant comparison requires that data be analysed from the beginning of the study. This enables any newly identified and important themes to be incorporated into subsequent data collection and allows for the development of the most salient points from participants' perspectives.

Qualitative data were generated through focus groups and semi-structured interviews. Expressions of interest to participate were sought by a Research Midwife who also recruited to the focus groups via the Principal Investigator (PI) at each hospital. A purposive sampling frame was used (i.e. a non-probability sample assumed to be representative of the population), within which self-selection occurred. Recruitment was restricted to key groups of health professionals and health care staff known to provide face-to- face care to women and their families in stillbirth.

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

Six focus groups and two semi-structured interviews were conducted in total. One focus group was conducted at site A, (n = 16), three at site B (n = 26) and two at site C (n = 18). 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 profession focus groups generated the most animated discussions and, possibly for this reason, were the most informative. The semi- structured interviews were conducted at site C after all focus groups were completed.

Focus groups

Early focus groups began with an open ended, core question: 'What experiences have you had in managing stillbirth?' whereafter 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 key issues for participants. There were, 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 h before delivery. These themes emerged in the earlier focus groups as important to participants.

The same researcher led all focus groups with a research assistant participating in one focus group. Focus groups lasted between 40 min and 2 h and took place before rounds, during a lunch break or as part of a scheduled research day. The interviews lasted 30–45 min.

Data from the focus groups and interviews were audio recorded and focus group recordings were transcribed by a third party. Interview data were transcribed by the researcher. Data 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 were explored 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 first, the nature of the evidence base and the (in)ability of mothers (and their partners) to make the 'right' decisions when faced with an emotive, stressful and time pressured life event such as stillbirth. These themes emerged in the context of discussions in two substantive areas: caesarean section versus normal (vaginal) delivery in stillbirth (Fig. 2) and going home or remaining in hospital for 48 h before delivery (Fig. 3).

Those health professionals citing the research evidence, whilst acknowledging its inadequacy, emphasised the need for patient choice, whereas those citing established, or traditional, practices and local contexts emphasised professional guidance. These two approaches to stillbirth were clustered around different sets of attitudes, values and understandings, or 'discourses' (Fig. 1). Importantly these discourses cut across professional boundaries.

Science versus tradition/localised practices

The scientific discourse highlighted the lack of high quality evidence in stillbirth management, whilst it was acknowledged that generating such evidence was difficult, if not impossible (Fig. 1). This created an obstacle to changes in practice. A universalising theme could also be found within the scientific discourse, which emphasised emotional universality and homogeneity; that is, that all women have the same emotions in stillbirth, though their needs may differ in how the event is managed.

In contrast, those operating within the traditional discourse, claimed that even high quality evidence would not change their practice because their approach was individualised to the needs of each mother. Within this approach the theme of emotional heterogeneity was evident; that is, the emotions of women in stillbirth were different. Paradoxically, as will become evident below, standardised management was advocated from within this discourse. Follow-up with individual women who had experienced stillbirth was suggested as more beneficial than research evidence to indicate 'what worked'.

The same dichotomy could be detected in issues such as reducing the stillbirth rate. Whereas the scientific discourse acknowledged recent findings, the same were met with some scepticism within the traditional discourse and the evidence was not considered universally applicable nor directly transferable to the North East of England, with its particular demographic and cultural characteristics.