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A qualitative study exploring the experiences of bereavement after stillbirth in Pakistani, Bangladeshi and White British mothers living in Luton, UK.

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Conflicts of interests

None to declare

Ethical approval and consent to participate

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Abstract

Aim

This study aims to explore the experiences of bereavement after stillbirth of Pakistani, Bangladeshi and White British mothers in a town with multi-ethnic populations in England.

Participants

A purposive sample of Pakistani, Bangladeshi and White British mothers aged over 16 (at time of infant birth), who suffered a stillbirth in the preceding 6-24 months and residing in a specified postcode area were invited to take part in the study, by an identified gatekeeper (audit midwife) from the local National Health Service Trust, in addition to local bereavement charities.

Design

Qualitative methods using face-to-face semi-structured interviews were undertaken, recorded and transcribed verbatim. Using framework analysis, several themes were identified.

Findings

There were three main themes identified from the data; 1. knowledge and information of pregnancy and perinatal mortality; 2. attitudes and perceptions to pregnancy and perinatal mortality and 3. experiences with maternity care. The findings revealed mostly similarities in the bereavement experiences of the Pakistani, Bangladeshi and White British mothers. A few cultural and religious differences were identified.

Conclusions

This study found important similarities in bereavement experiences of Pakistani, Bangladeshi and White British mothers and highlights considerations for policy makers and maternity services in how the timing of bereavement after care is provided, including advice surrounding the infant post-mortem.

Keywords:

White British, Pakistani, Bangladeshi, stillbirth, Experience, Risk Factors.

Journal Pre-proof

Background

The experience of stillbirth is associated with adverse outcomes for mothers including, anxiety, depression, and post-traumatic stress disorder (Downe et al., 2013a; Gravensteen et al., 2013; Heazell et al., 2016; Murphy and Cacciatore, 2017), and also linked to detrimental effects on subsequent pregnancies, with mothers having a higher risk of a further stillbirth (Flenady et al., 2011). Unlike other bereavement experiences, for instance, the death of elderly parents, stillbirth affects both parents simultaneously, resulting in limited emotional resource and mutual support (Downe et al., 2013a). This situation is then further compounded by the social stigma associated with stillbirth (Brierley-Jones et al., 2015).

Figures in the United Kingdom show ethnic disparity in the prevalence of stillbirth, with Pakistani and Bangladeshi mothers showing disproportionately higher rates (10.2 and 8.7 per 1000 live births respectively) compared with white British mothers (5.9 per 1000 live births) (Office of National Statistics, 2017). Despite the increased numbers of Pakistani and Bangladeshi mothers experiencing adverse birth outcomes, there is a paucity of research that explores the UK context of their stillbirth experience.

Bereavement research with parents who have experienced a stillbirth has been protracted, due to ethical and sensitivity considerations. The majority of existing studies to date have utilised survey methods (Bond et al., 2018; Downe et al., 2013b; Gravensteen et al., 2013; Inati et al., 2018; Redshaw et al., 2014). While, these studies may be considered less intrusive (Sque, 2000), it focuses the bereaved mothers attention upon the deductive questions pertinent for the researcher. However, this detracts from the opportunity to gather inductive insights, which are better obtained using more personal methods, such as interviews (Headland et al., 1990; Silverman, 1993). A few studies have used qualitative methods and face-to-face interviews, however, while the majority of the existing research on experiences of stillbirth has accessed the narrative from white British women (Murphy and Cacciatore, 2017), some studies have failed to report maternal ethnicity, or Black Asian and Minority Ethnic (BAME) mothers are underrepresented in the study cohort (Downe et al., 2013b; Murphy, 2013; Rådestad et al., 2014; Redshaw and Henderson, 2014). Alternatively, the research is not comparable with a UK context as research has been conducted in developing countries (Sutan and Miskam, 2012). At present, the current evidence base homogenises the existing narratives into broadly ‘mothers experiences’ and has failed to identify bereavement

experiences in diverse settings, with Pakistani, Bangladeshi and white British mothers. This study addresses this lacuna.

Methods

Qualitative methods using face-to-face semi-structured interviews were selected as the most appropriate method to achieve the research aim. Both ethical and methodological considerations for this study were guided by the '*Framework for ethical decision making*' when undertaking research using bereaved families (Sque et al., 2014). This paper follows the recommended criteria reporting qualitative studies (COREQ) (Tong et al., 2007). This study forms part of a wider convergent mixed-method study, examining inequalities in perinatal mortality in Pakistani, Bangladeshi and white British women, living in Luton. The results of which are published elsewhere or currently in review (Garcia et al., 2017, 2018, 2015; Garcia, 2017). The findings from this part of the wider study were considered important in their own right to be published in a single paper.

To protect patient confidentiality and minimise distress, the research team worked with a gatekeeper (the hospital's Audit Midwife) to identify and recruit potential participants (Sque et al., 2014). The hospital sent potential participants a recruitment pack with a reply-paid opt-in or opt-out contact sheet. The bereaved mothers were offered the choice of the interview venue as their own home, a room in a local community centre, or a room at the University. If the bereaved mothers replied and provided contact details, the research team invited the bereaved mother to be interviewed at the venue of their choosing). Recruitment took place between December 2014 and March 2016.

Before commencement of the interviews, participants were invited to discuss any questions regarding participation in the research, and then they provided informed written consent. RG conducted the interviews (RG is a female, registered nurse, and had experience in dealing with sensitive issues also undertook the NHS training '*Good Clinical Practice*' to further safeguard the participants and as a condition of the ethic approval being granted). Although the research team were prepared to conduct interviews in Urdu and Sylheti, this was not required. The interviews were audio recorded. Post-interview bereavement support was available (if required) to manage potential distress.

Participants

Retrospective and purposive sampling of bereaved mothers was undertaken. Therefore a pre-determined and fixed-sample of women were identified and contacted to be invited to take part in this research (Teddlie and Yu, 2007). The identified homogenous group was: 'mothers', 'pregnancy', 'birth', 'loss' and 'motherhood' all of whom have experienced stillbirth, to provide insight into their bereavement experience of stillbirth. Furthermore, purposive sampling further ensures representation from Pakistani, Bangladeshi and White British women (Lakhanpaul et al., 2014).

Inclusion and exclusion criteria

Mothers were identified by the gatekeeper using the following inclusion and exclusion criteria; *Inclusion*: delivered their infant in the previous 6 to 24 months, the infant was either delivered as a stillborn or died within seven days of being in the neonatal intensive care unit, aged over 16 at conception, maternal ethnicity of Pakistani, Bangladeshi or White British documented in their records, residing within fixed postcode areas of the town.

Exclusion: women who had delivered infants but earlier than the preceding six-month bereavement period (Sque et al., 2014), retrospective records showing bereaved infants over 24 months (to eliminate retrospective bias and inaccurate memory recall), women aged under 16 years of age at the time of conception, maternal and ethnicities other than Pakistani, Bangladeshi and White British, and not living in the predefined postcode areas. A total of 29 mothers meeting the inclusion criteria were identified and invited to participate, and six mothers consented and took part in the semi-structured interviews, providing a 21% response rate.

Data collection

A semi-structured topic guide was developed by reviewing the existing evidence in the area and to meet the research aim. The topic guide was piloted by RG and NA with a bereaved mother (>10 years earlier) to establish the sensitivity and relevance of the tool. Following this valuable exercise, the topic guide was revised to contain an open-ended question (following structured questions determining demographic data), which invited the mother to tell the researcher her bereavement story. The piloting exercise revealed that the pre-determined questions that were being sought as part of this study, were likely to be shared with the researcher during the course of natural conversation. Furthermore, this approach was less

intrusive and facilitated an equal balance of power between participant and researcher (Atkin, 2006; Mens-verhulst and Radtke, 1991). Maternal education was used as a proxy for deprivation, in addition to the use of identified postcode areas. Maternal education has been shown to be a reliable indicator for socioeconomic status in migrant women (Blumenshine *et al.*, 2010; Mceachan, 2012; Zeitlin *et al.*, 2016). See appendix 1 for the topic guide.

Ethnic classification

The NHS uses predefined classifications to describe ethnic categories, which are coded according to the 2001 UK Census and NHS mandatory set. (Department of Health, 2008). For the purposes of this study, NHS categories were used, consequently, maternal country of birth, generational status and length of residency are unaccounted in this paper.

Ethical approval

Ethical approval was provided by University of Bedfordshire Institute for Health Research, (IHRREC442, November 2014) and NHS ethics committee (15/EE/0181: 157751, June 2015). Additionally, this research was funded by the Steel Charitable Trust (for RG to undertake Doctoral research), under the supervision of NA and GR. The funders were not involved in the study or publications.

Several strategies were undertaken during the interviews to support the participants in the event that they experienced distress as a consequence of taking part. This included providing culturally sensitive bereavement support contact information, and a notice of participation letter was also sent to the mothers' general practitioner, which provided the same contact information. These organisations were contacted prior to undertaking the study to seek confirmation and advise, ensuring they were the most suitable organisations.

Data Analysis

The audio recordings were transcribed verbatim by RG for the interviews and NA randomly checked the audio and transcripts for accuracy. In addition, one transcript was passed back to a participant for validation of the trustworthiness of the transcript, having been an accurate record of the interview (Ritchie and Lewis, 2003; Srivastava and Thompson, 2009). Demographic data was extracted from the transcripts and this data was entered into a Microsoft Excel file in order to produce a descriptive account of participant characteristics. Additionally, Microsoft Excel was used to organise the data, using Framework Analysis (Ritchie and Lewis, 2003) in five stages, generating the themes; being immersed within the

data, familiarisation of the narrative, identification of emergent themes, building the framework, and finally, indexing and schematic charting this data to interpret the findings (Dixon-Woods, 2011; Srivastava and Thomson, 2009). Framework analysis is an accepted method for organising large quantities of data quickly, in a more systematic way than thematic analysis and was considered suitable for this study (Gale et al., 2013; Richie and Spencer, 1995).

Findings

All the interviews took place in the participants' homes, at their request. A total of 6 participants took part, all who had suffered a stillbirth; 5 of the mothers were born in the UK, while one Pakistani mother had lived in the UK for 15 years. Only one mother had her partner present (in the property) while the interview took place, all other mothers were alone. Table 1 shows the participant characteristics. The audio recordings ranged from 32 minutes to 1 hour 35 minutes.

Table 1: Participant characteristics of the interviews

Participant	Ethnicity	Highest Qualification	Living arrangement	Employed y/n	Smoking status	Reported pregnancy
1	WB	B-Tec	Partner & child	Part-time	No	4 weeks
2	Pakistani	A Level	Partner and child	No	No	6 weeks
3	Pakistani	GCSE	Partner and child	No	No	5 weeks
4	Pakistani	A Level	Husband and parents -in-law	Full-Time	No	4 weeks
5	WB	A level	Partner and child	No	No	4-5 weeks
6	Bangladeshi	B Tec	Partner and child	No	No	8 weeks

There were 3 main themes that emerged from the data; knowledge and information about pregnancy and perinatal mortality, attitudes and perceptions to pregnancy and perinatal mortality, and mothers' experiences with maternity services. The themes and sub-themes are shown in figure 1 and discussed according to their similarities or differences, using narrative extracts from the interview transcripts.

‘Knowledge and information of pregnancy and perinatal mortality’.

The narratives revealed similarities in that all the mothers regardless of their ethnicity, felt that their prior knowledge of stillbirth and adverse pregnancy events was very limited and that they felt were unprepared for adverse birth outcomes despite receiving other pregnancy-related information early in the pregnancy. Moreover, they had presumed that they would be

aware of the warning signs, if anything deleterious was to occur. This is seen in the following narrative extract from a Bangladeshi mother;

For first Mums I think there needs to be more information out there....I used to think about stillbirth, ...I thought no, that's not going to happen it's just like, you know, I will know the signs and I honestly did think –that's why it happened to me 'cause I thought nothing is going to happen to my baby, my baby is healthy...I do think there needs to be more information for first Mums if needed.

Bangladeshi, Mother 6

It also emerged that all the mothers thought that pregnant mothers needed to receive more information about the potential problems and associated outcomes in pregnancy;

First, mums, I think there needs to be more information out there. I think if they (want?) it first Mums are more happy and, you know ... I do think there needs to be more information for first mums if needed, they need to be there

(Bangladeshi mother, 6).

Some differences emerged from the cultural beliefs in the data of Pakistani and Bangladeshi mothers. It was explained by one Pakistani mother, how pregnant mothers 'back home' more readily followed in cultural health behaviour, for instance, by not interacting with other mothers who had experienced a stillbirth or miscarriage through the fear that the 'bad omen' would pass to the pregnant mother.

... the people from ... back home and like the older generations believe it. With me what my mother-in-law said to me, for example, the lady across that road had a miscarriage and she invited me to a party a week before I lost my daughter and they put it [my stillbirth] down to her giving me, you know, the bad (chuckles) the bad omen and that's why I lost my child. And you know, 'cause you're sort of messed up in the head for a little while you might even believe that, because you want to believe something else, isn't it?

(Pakistani mother, 2).

Further differences were found in cultural beliefs of Pakistani and Bangladeshi mothers on certain food restrictions during pregnancy, such as avoiding papaya (fruit), since it is believed to induce inter-uterine bleeding or miscarriage, or the mothers consuming restricted protein amounts.

Like, they say that fruit, papaya, you shouldn't eat that ... when you're pregnant when you find out you shouldn't eat that 'cause

you can suffer a miscarriage and, erm, it's like so there's a lot of foods that you have to avoid at that stage so at the start you couldn't eat lots peanuts.... (Pakistani mother, 3).

'Attitudes and perceptions to pregnancy and perinatal mortality'

Similarities were identified with all the mothers regardless of their ethnicity, when discussing their feelings of anxiety which occurred throughout the bereavement process. Firstly, feelings of anxiety were experienced by the mothers around the unfolding events as they discovered that something was amiss with their babies. Secondly, anxiety focused around the situations of learning their baby had died, and lastly, feelings of anxiety were reported for future pregnancies. The following extract depicts a mothers' anxiety as initial events unfolded;

So, the doctor come in and confirmed there was no heartbeat and explained that... I automatically thought I just want it over, I just want (inaudible) to get the baby out; I said, "*I can't go through this*".

White British, mother 5

Additionally, all the mothers discussed how they perceived the timing of the death to be related to an incrementally increased grief experience, for example, miscarriage was considered a 'lesser' trauma than a baby dying in the first few days. This is seen in the following extract;

I know it's a hope and a dream, but it's not a real baby, it doesn't have, limbs, it doesn't have, you know, it wouldn't have had a heartbeat at that point..... but [name] her babies lived months and then they were born and I say to her I can't even begin to imagine what that's like to see their eyes, to have them alive in you and then to have them taken... it's like my friend that lost her boy at twenty-three weeks she said, "Oh, you've been through far worse, you had the nursery ready..."...

(White British mother, 1).

Attitude to screening tests and post-mortems

The narratives from several mothers revealed that they believed that the foetal anomaly scan had a significant risk of harm to their unborn baby and this contributed to their decision not to undertake the test. Furthermore, two mothers (Pakistani and Bangladeshi) described their perceptions of stress surrounding screening tests and the post-mortem (PM) offered afterwards, the stress impacting their decision to not have the test. This is seen in the following:

– the midwife said "I'm getting the leaflets", she explained beforehand as well everything - it [post-mortem] was just

something I didn't want to get done I think. Maybe I was too nervous going on the tests and everything because of the scans and it was too much and then going for the blood tests and everything and it was just too much.

(Pakistani mother, 2).

Several issues were raised regarding the mothers' decision whether to have the baby undertake a PM. Firstly, all the mothers described the idea of the deceased baby being 'pulled around' as distressing, and the mothers' expressed misunderstanding around PM examinations occurring without parental consent and the idea of a 3-month delay in obtaining the PM findings was poorly understood. Differences were identified in terms of religious belief; one Bangladeshi mother described how her Islamic beliefs prevented her from having a post-mortem after the baby's death:

Basically – it's obviously that we believe that you shouldn't have it [post-mortem] done because you should go the same way you came. So, when she was buried we didn't want to change the way that – we didn't want to put scars on her or anything like that; that's why.

(Bangladeshi mother, 6).

However, one Pakistani mother explained that she would have taken up the opportunity for an external examination (i.e. MRI scan) had it been offered. This is evident in the following extract;

...we wouldn't have the internal, no doubt about it - wouldn't have had him sliced around, but we might have had the external scan type thing - that might have shown something.

(Pakistani mother, 2).

Similarity was seen in all the mothers narratives, describing intuitive feelings that something was wrong with the pregnancy or the baby; the participants described having 'thoughts' or 'feelings' that something was wrong with the baby/pregnancy. This is seen in the following extracts;

Just knew there was something wrong and my husband come back ...and I go to him, "Look I just don't feel right"; ...so she [midwife] sat me down, and she checked me and she goes to me, "I don't want you to get upset, you know, I can't really find a heartbeat but sometimes a baby is back for you towards the stomach, so maybe it's that, don't worry, don't worry, go...", you know, "...go to the hospital". But I just knew.

(Pakistani mother, 4).

The perception of feeling a ‘burden on others’ was also expressed by all of the mothers. One mother explained how prior to the confirmed death of her baby, she thought she was being a ‘burden’ to the staff, and she perceived that other women’s’ needs were greater than her own. This is shown in the following extract;

But it was the fact that I was made to feel like a burden which was the thought I had before,...they've [staff] got so much to do, again, you're thinking about other people - you think, you know, all these people that they're inducing up there...they could do without me taking up a bed, taking up their time, you know, again you put yourself at a lower scale than everyone else.
(White British, mother 1)

Two mothers also described their fear of being judged negatively by healthcare staff by asking ‘silly’ questions. This is seen in the following;

I think that's what a lot of mums feel, they feel judged for asking silly questions or – especially the first five months like going to hospital and stuff you might think, “Oh I'm just being silly - I'm not going to go”, but it could be the difference between saving your baby or any complications or how you help the baby
(White British, mother 5)

‘Experiences with maternity services’.

There were further similarities evident in the mothers’ experience with maternity services. For example, the mothers spoke at length about their antenatal and bereavement experience with healthcare staff and services. At the point at which they delivered their stillborn baby, all the mothers described their care as ‘good’ or ‘very good’. One mother explained how the midwife was especially attentive to her needs and carefully provided explanations to the bereaved mother. Furthermore, the midwives and staff were described as, personal, friendly and supportive and this perception extended beyond the time of the delivery of their deceased baby;

I had two midwives; one was a student, and one was the regular there. The regular lady she was so generally, like, caring and she actually put – like she put a smile on my face when even my mother couldn't put a smile on my face, she was so caring and she (inaudible) when I delivered my son she came to my room, ...and she gave me a big hug, and she was, like, “Oh my God he looks just like her”. And she was generally just so caring
(Bangladeshi mother, 6).

The mothers also shared their negative experiences. Poor communication was evident with a few mother's bereavement experiences, resulting in undue distress for the mother. For example, one Pakistani mother described experiencing delays in staff returning phone calls outside routine appointment time and a visiting midwife (to check on the newly arrived baby and postpartum mother) had not been informed of the death and both mother and midwife were unprepared for the unexpected visit. This is shown in the following;

...then the midwife, my community midwife, walks in and that's it, I'm gone [crying]. She was, like, "*You didn't come to see me today - I come up to find out where you were - I thought you might have started bleeding again, I can't believe it*" – and she actually had to walk out and said, "*I can't deal with this*" and walked out. ... she didn't know...
(White British mother, 1).

Furthermore, one Bangladeshi mother described how the midwife did not warn the mother of the visually deteriorated (i.e. macerated) state of the baby, resulting in distress;

They didn't warn me about that [condition of the baby] –...but she just goes to me, "She might be blue or she might be purple"; she was almost like pickled pears like the only thing she had that was okay was her hands and her feet everything else was – her skin was peeling...
(Bangladeshi mother 4).

Similarities in the mothers experiences were identified once the death of the baby was confirmed. For instance, most of the mothers were given medication to induce labour and were asked to return home, or to wait on the ward with other mothers who were waiting to deliver their live baby. Irrespective of where they decided to labour, the mothers found this wait distressing. Additionally, the mothers described mixed views on whether to take the dead baby home;

...it was like, "*Well you've got to take the baby home*". They had to put the baby in the car seat and (inaudible) in the car and try and (inaudible) with that baby and it was like – I think that, for me, would have been worse than driving home with an empty car seat, which is what we did.
(White British mother, 5).

Several mothers described challenges with counselling services. For example, a telephone consultation with a male counsellor, and initial contact (by the service) being made too early in the bereavement journey:

I wasn't going to have it [bereavement counselling]. They called me two days before the [name] funeral - I was not in any fit state to speak to anyone and I was, like, I don't want to speak to anyone blah, blah, blah and that was it, I was struck off the record. Now had they called me a week later possibly, or a couple of months later or six weeks later or something, the outcome could have been different ...

(White British mother, 1).

Similarity was found between the mothers describing emotional and practical support during their bereavement experience. One mother explained that no staff checked what specific and appropriate support was available to the mother;

They just send you home without no support, either here you live with people who are having babies, live in the ward with them, or go home where you've got all these relatives and everyone is just fussing over you and you just want to be left alone, 'cause your whole world has just collapsed

(Pakistani mother, 4).

The mothers described needing to be emotionally strong to meet the needs of other family members (including grandparents and siblings), in contrast to addressing their own grief. This is seen in the following extracts,

...people were coming for to pay respects and condolences and they were all really surprised that I really held myself – like I was very strong. It's not being strong it's just that I've got very ill parents, my dad had a stroke, Mum suffers from depression, my father-in-law suffers from Parkinson's, mother-in-law is ill, so I just didn't want them worrying about me. So you just always have to, like, even put a guard up, I'd rather cry in my room but I won't cry in front of them so, just had to be strong for them, for my family, ...

(Pakistani mother, 4).

All the mothers explained the difficulty that they experienced in discussing miscarriage and stillbirth with other people, due to the sensitivity of the topic. This is seen in the following;

... some people, like customers and patients like, if they saw me they were, like they would ask me “*Have you had your baby?*”? And if you tell them they just don't know what to say, they just say they're sorry, like no one wants to talk about it, it's just brushed under the carpet, “*So sorry to hear about that*” but then they won't ever say that again. Even at home I find my family talks about it but my in-laws they kind of brush it under the carpet, no one really talks about.

(Pakistani mother, 4).

Cultural needs

Differences emerged in the cultural beliefs of Pakistani, Bangladeshi and white British mothers. For example, one Bangladeshi mother discussed the issues of privacy during pregnancy and concealment. She explained pregnancy is not openly discussed in Bangladeshi or Pakistani cultures, in contrast to Western culture. She suggested that this was due to fear of misinformation being spread within the community;

“Oh I don't want to share my story with another girl and then she could go home, and she could talk about, you know, my issues”. And, you know, say like I said to you about my husband and my mother-in-law, that could be portrayed in another way in another household and the Asian community is being portrayed in a different way, it is really private, and it is really hard to talk to another that you don't know, you know, about what you're going through because it can be taken another way and it could come back to you...
(Bangladeshi mother, 6).

Additionally, it was explained that in Pakistani and Bangladeshi families, the process of grief is frowned upon, which leaves the mother feeling unsupported;

...with the Asian community it's something to look down on, you know, you don't have to grieve, what are you grieving for, in fact there's something bad to grieve, and it's really stressful, and you feel like you're only – you're going through it yourself no one is supporting you around you
(Bangladeshi mother, 6).

Discussion

This paper explored bereavement experience of Pakistani, Bangladeshi and White British women. Most of the findings in this study demonstrate similarities in bereavement experiences of the mothers regardless of ethnicity. Three main themes emerged from the narrative in this study; knowledge and information of pregnancy and perinatal mortality, attitudes and perceptions of pregnancy and perinatal mortality and experiences of maternity services. Similarity in bereavement experience between Pakistani, Bangladeshi and white British mothers has not been explicitly discussed previously, therefore contributing to new knowledge. Cultural differences between the maternal ethnicities were found, such as eating restrictions during pregnancy or religious views that contributed to decision-making when considering the option to have a post-mortem examination. Consistent with other scholars, we

found all mothers regardless of ethnicity had limited pregnancy-related knowledge which further contributed to their decision-making (Cacciatore, 2010; Kelley and Trinidad, 2012). However, further study is required to discern how and if, these cultural differences may contribute to the mother's stillbirth experience.

Congruous with previous research (O'Leary and Warland, 2013; Rådestad et al., 2014; Trulsson and Radestad, 2004), similarity was found in all the mothers described intuitive feelings that something was wrong, and perceived feelings of anxiety and stress before the death was officially confirmed (Geller, 2004; Woods et al., 2010). Further similarity was found with all mothers describing the adverse impact of stillbirth on the wider family, reporting it was difficult to discuss openly, consequently, the mothers found themselves in a lead role supporting their family. While the wider impact on the family has been acknowledged in previous work (Boyden et al., 2014; Cacciatore, 2010; O'Connell et al., 2016)(O'Neill, 1997), this study demonstrates similarity with the mothers, regardless of their ethnicity, in being a central supportive role in the entire family, during this period of grief.

Differences between mothers focused around culture and religious beliefs during pregnancy. For example, one important difference found that pregnancy was not openly discussed in Bangladeshi families, unlike Pakistani or white British families. This potentially places a Bangladeshi mother at a disadvantage to not sharing accurate health messages between peers. This finding further confirms the need for researchers to discern the differences between South Asian groups, to identify nuanced information that may adversely mediate a mothers health behaviour (Garcia et al., 2015). Further cultural differences were identified in Pakistani and Bangladeshi mothers beliefs, around prohibitive and permissible foods during pregnancy, thought to be helpful or harmful during pregnancy. This study did not identify specific cultural beliefs involving food restrictions in white British mothers, however, this may be a methodological artefact insofar that the dominant advice for food restrictions centres on the majority of western food items, therefore may be considered normative, consequently, not discussed (National Institute for Health and Care Excellence, 2008).

This study also found differences between Pakistani, Bangladeshi and white British bereaved mothers in that culture and religion was central for Pakistani and Bangladeshi mothers in their decision-making for not undertaking post-mortems. This finding contributes further to the current nebulous evidence base (Algren et al., 2015; Breeze et al., 2012; Lewis et al.,

2018; Rankin et al., 2002). However, it is recognised that the sample size in this study is small and further exploration is necessary to understand how prolific this finding might be in stillbirth bereaved Pakistani and Bangladeshi mothers.

This study has some strengths. This is the first study to explore the stillbirth bereavement experience in Pakistani, Bangladeshi and white British mothers. Consequently, this study provides rich description using qualitative methods (Silverman, 1993), contributing to scholars and clinician understanding of the mothers bereavement experience. Furthermore, this paper presents important similarities found in the experience of stillbirth from the mothers who took part in this study. These homogenous findings will enable service providers to develop suitable interventions and address the areas highlighted by the findings. Importantly, cultural and religious findings were also identified, and this knowledge can further contribute toward to service providers developing culturally appropriate care after a stillbirth experience.

It is recognised that the sample size in this study is small, however recruitment achieved a 21% response rate from invited participants, which is considered to be good, given the small number of potential participants eligible to take part, the restrictive inclusion criteria and the sensitive nature of the research (Sque, 2000; Sque et al., 2014). Future research should consider including mothers who are unable to speak English, and a larger sample size for all ethnic groups, so that policymakers can fully understand the intersection of a range of factors upon the bereavement experience (e.g. ethnicity, social class, language, etc). Together, however, this paper provides a valuable contribution to the current scarce evidence-base of the bereavement experiences in hard to reach bereaved Pakistani and Bangladeshi mothers.

Conclusion

The findings from this study demonstrate mainly similarities in Pakistani, Bangladeshi and white British bereaved mothers experiences after stillbirth, with a few cultural and religious differences identified for Pakistani and Bangladeshi mothers. This study further highlights the need for considerations in stillbirth bereavement care, such as understanding the mother is a central support role within the wider family after experiencing a stillbirth. Furthermore, healthcare staff need to carefully explain post-mortem and antenatal screening procedures,

rights and consequences and recognise that many women have restricted health literacy in respect of stillbirth. The findings from this study can contribute to the development of culturally competent bereavement care for mothers who have suffered a stillbirth.

5474/5000

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Abbreviations

White British	WB
National Health Service	NHS

Consent to publish

Informed and written signed consent was provided by the participants prior to taking part in this study.

Availability of data and materials

No additional data is available

Authors contributions

[removed for peer review]

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Appendix 1 – Topic guide

CLINICAL EXCELLENCE, QUALITY & SAFETY

Explaining factors that contribute to low birth weight, stillbirth and infant mortality in Pakistani and Bangladeshi women living in Luton

Topic Guide – Bereaved Mothers

1. Introduction

- Thank you for agreeing to take part.
- Give background & purpose to study: we want to identify factors that may contribute to low birth weight, still birth and infant mortality in babies of Pakistani and Bangladeshi women in Luton. This will help identify areas to improve maternity services in the future.
- Acknowledge the loss of their baby.
- Acknowledge that the topic is upsetting / sensitive. If they want to have a break at any time (and stop the recording) that is absolutely fine.
- Check what support is in place for after the interview/after that day (i.e. who), signpost to counselling services (give contact numbers).
- Explain the consent procedure, right to withdraw, confidentiality and audio recording of the discussion. Break at any time if required. Interview discussion to last 60-90 minutes. Check that they have understood the information sheet, confidentiality information and check understanding.
- Explain how the discussion that is going to take place will be used in the research.
- Findings form part of PhD thesis and will be published in academic journals and findings feedback local presentation to local service providers and interested community members.
- Complete consent forms, bio questionnaire.

Rapport building *[build on answers to establish rapport]*

How do you self-define you ethnic group?

Probe: Pakistani, Kashmiri, Bangladeshi, Asian, Asian British, Muslim, English

Have you lived in UK long?

Probe: since birth or migrated when?

Where did you go to school?

Probe: location (UK or abroad), level of education attained.

Tell me about who lives at home with you?

Probe: for husband/partner/children/parents/parents-in-law.

Do you work?

Probe: for home-maker, house wife, carer, employed work, if employed what work.

For the purposes of completeness, can I ask whether you smoked or drank alcohol during your pregnancy?

Probe: how much/how often.

1. The mothers story and context

I would really like to start by hearing about you and your and experience. Is that okay?

When did you first realise that something may not be right with your pregnancy?

- *Probe: for thoughts on your pregnancy, what signs suggested something was not right, e.g. decreased foetal movements, vaginal bleeding/discharge, stomach cramps, swollen ankles, "feelings something was wrong".*
- *Probe: for views on when in the pregnancy did something go wrong? (first pregnancy, second pregnancy etc).*
- *Probe: what actions you took when you realised something was wrong e.g. friends, family, GP, A&E, Midwife, Obstetric ward, NHS Direct/111*
- *Probe: for views on what actions others took? Partner, family, GP, hospital staff.*
- *probe for: any actions taken or not taken that are important to you in respect of your culture? What support did you receive?*
- *Probe: for what happened next e.g. the delivery, what follow up received?*
- *Probe: what aftercare and/or counselling support did you access/receive (if not, why not, views on counselling support if received.*

I would like to hear your views on what you think went wrong.

- *Probe: for thoughts on why things went wrong in the pregnancy (personal health behaviours, access to care, help seeking behaviours, co-morbid factors, Gods will, genetic/hereditary factors or family history.*
- *Probe: for thoughts on the reasons behind decisions made (e.g. screening); autonomous or collaborative decision making e.g. Husband, family decision, doctors' advice and why?*
- *Probe: for services accessed, post morte, MRI (if not why not).*

2. Your experiences of maternity services and maternity healthcare professionals.

I'd like to ask about the issues related to your experience of maternity services and maternity healthcare professionals in Luton.

How were you referred to maternity services in Luton at the beginning of the pregnancy?

- *Probe: for referral route, how referred*
Probe: for how many weeks gestation at referral and factors influencing decision.

What maternity services did you access?

- *Probe: for views on maternity services – lifestyle changes; preconception (preconception advice from GP), antenatal (booking, screening tests, specialist screening services, surveillance, antenatal class, birth preparation), specialist clinics (diabetes or hypertension), bereavement follow up (consultant or GP), bereavement midwife.*

I would like to ask you your views and experience of antenatal tests and checks (i.e. screening) services?

- *Probe: for experience of when in pregnancy, by whom, and if known why e.g. cousin marriage, hereditary risk.*

- *Probe: for experience and awareness of screening services/conditions (Downs syndrome, Thalassaemia, normal growth/development and infectious diseases)*
- *Probe: for what information was provided, understanding of opting in or out of screening services, sufficient information to make confident decisions regarding pregnancy and risks/benefits of these decisions and impact of information on future pregnancies.*
- *Probe: for what views on decisions made e.g. screening vs. no screening, reasons for decision?*
- *Probe: for your views of religious reasons (perceptions of Fatwa), Gods will.*

In your view are there any reasons why you (or other Pakistani/Bangladeshi/White –delete as appropriate) women) in Luton wouldn't use the local maternity services?

- *Probe: for views on favouring alternative healthcare (herbalists, traditional healers), pregnancy being a natural event and therefore not needing medical intervention, concealment/secretcy of pregnancy, lack of information of available services, unaware of benefits of services, fear of advice (termination of pregnancy), conflicts with cultural and religious beliefs, transportation problems, lack of confidence and trust in the service providers e.g. receiving misinformation/inadequate, biased or stereotyped information, previous experience of self or others poor outcomes, language and communication problems, lack of female staff/separate facilities for women, lack of understanding toward cultural and religious choices*

3. Knowledge & information

I'd like to discuss with you what you know about the services that are offered in Luton for pregnant women and where you got your information and advice about your pregnancy from.

What does the Luton maternity service offer to local women?

- *Probe: for views on awareness of available services at preconception (preconception advice from GP, folic acid, healthy eating), antenatal (booking, screening tests, surveillance, antenatal class, birth preparation), follow-up afterwards (consultant, GP)*
- *Probe: for views on who provided this information friends, family, Internet, television, radio (which stations) GP, midwives, health visitors, others (identify).*
- *Probe: for your ideas and perceptions of caring for yourself during pregnancy-what to do and what not to do. Medication during pregnancy verses allopathic or traditional medicine. Nutrition (eating down, vitamins). Work, rest.*
- *Probe: for views on whether information provided was enough to prepare you for the pregnancy and if not why not, cultural perceptions of the services.*

Was the information provided accessible and acceptable?

- *Probe: for views on what form the information was provided (oral, written).*
- *Probe: for views on whether the information understandable, any communication issues like language/literacy, if interpreters were available to ease communication, where they used.*
- *Probe: views on whether any part of the service impacted on patients cultural and religious values e.g. availability of female staff, screening advice, termination of pregnancies, informed choice.*
- *Probe: for information on autonomous/collaborative/guided decision making and what was important during this process.*

- *Probe: preparations for burial, washing, dressing, prayers materials.*

4. Views on low birthweight, stillbirths and infant mortality

I would like to talk about your views on ...[select appropriate: low birthweight or stillbirth or infant mortality].

**Use only the appropriate section(s) below to reflect the mothers' bereavement story:*

Low birth weight (pre-term deliveries or small for gestational age)

What do you understand is low birthweight?

- *Probe: views on reasons birthweight less than 2500 g or 5.5lb, small babies=healthy/unhealthy, growth restricted.*

What are the risk factors for low birthweight?

- *Probe: views on biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, , family genetic/hereditary history, cousin marriage, age, previous complications, ethnicity, known risk factors, pre-term birth (before 37 weeks) God's will.*
- *Probe: views on cultural/religious perceptions: black magic (wind, curses), fatalistic explanations/Gods will.*

How can low birth weight be prevented, if at all?

- *Probe: views on adequate nutrition (Vitamin D, folic acid, iron, hot/cold foods, avoiding shellfish and high infection risk foods), regular ante-natal monitoring, ante-natal classes (education) termination of abnormal foetus (detected through screening), screening uptake, –screening for family genetic/hereditary history, cousin marriage ,*
- *Probe: views on cultural/religious perceptions avoiding cousin marriage, not smoking (including smokeless tobacco and betal nut) supernatural beliefs (avoiding the evening wind, curses, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*

Stillbirth

What are the risk factors for stillbirth?

- *Probe: views on reasons - biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, avoidance of cousin marriage, , age, previous complications, ethnicity, known risk factors, God's will.*
- *Probe: views on cultural/religious perceptions: black magic, fatalistic explanations/Gods will*

How can stillbirth be prevented, if at all?

- *Probe: views on adequate nutrition (Vitamin D, hot/cold foods, avoiding shellfish and high infection risk foods, folic acid, iron), regular ante-natal monitoring, ante-natal classes (education) termination of abnormal foetus (detected through screening), screening uptake,*
- *Probe: views on cultural/religious perceptions - avoidance of cousin marriage, not smoking (including smokeless tobacco and betal nut) supernatural beliefs (avoiding the evening wind, curses, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*

Infant death

What are the risk factors for infant death?

- *Probe: views on reasons biological factors – perceptions about the causes of poor birth outcomes: diet and nutrition, late booking, comorbidities, avoidance of cousin marriage, age, previous complications, ethnicity, known risk factors, God's will.*
- *Probe: views on cultural/religious perceptions: black magic, fatalistic explanations/Gods will*

How can infant death be prevented, if at all?

- *Probe: views on adequate nutrition (Vitamin D, hot/cold foods, avoiding shellfish and high infection risk foods, folic acid, iron), regular ante-natal monitoring, ante-natal classes (education) termination of abnormal foetus (detected through screening), screening uptake,*
- *Probe: views on cultural/religious perceptions - avoidance of cousin marriage, not smoking (including smokeless tobacco and betal nut) supernatural beliefs (avoiding the evening wind, curses, avoiding solar/lunar eclipses, amulets, enchanted water, prayer).*
- *Probe: views on breastfeeding (discarding colostrum), safe sleeping practices.*

5. Service improvements

I would like to ask you your views on how services might be changed.

Based on your experience, what are your views on how professional maternity staff in Luton might better meet your individual needs?

- *Probe: for advocates (or patient representative), female staff, female only antenatal classes, separate facilities for women.*
- *Probe: for culturally competent staff e.g. staff that have awareness of diverse religious, cultural beliefs, and different social needs (connectedness with others, friends, community), maternity services that empower and meet diverse needs, non-judgmental, and encourage inclusion and trust.*
- *Probe: for culturally appropriate services, i.e. how can things be done more culturally or religiously sensitive?*

What else could have been done to help you through your difficult time?

- *Probe: institutional support: for views on counselling and support services offered,*
- *Probe: professional support (staff) i.e. rapport, respect, empathy, listening,*
- *Probe: social support (partner, family, friends) i.e. respect, empathy, listening, acknowledgement*

If there was one recommendation you could make what would it be?

- *Probe: views on how services could be improved to support bereaved mothers*

6. Closing. Any other comments, suggestions or questions

I would like to ask you for your final thoughts reflections as we come to the end of our discussion.

You have been through a difficult experience and I am grateful that you have shared it. Your views are very valuable to us and we hope that you have not found it too distressing to share

your experience. Your views will help develop future maternity, as together with other women's experiences, we will be able to highlight areas for change to make improvements for mothers and their families.

Ask if they would like summary of the findings of the research?

Summarise key points of discussion

[signpost support services]

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Appendix 2 - Table 1

Table 1: Participant characteristics of the interviews

Participant	Ethnicity	Highest Qualification	Living arrangement	Employed y/n	Smoking status	Reported pregnancy
1	WB	B-Tec	Partner & child	Part-time	No	4 weeks
2	Pakistani	A Level	Partner and child	No	No	6 weeks
3	Pakistani	GCSE	Partner and child	No	No	5 weeks
4	Pakistani	A Level	Husband and parents -in-law	Full-Time	No	4 weeks
5	WB	A level	Partner and child	No	No	4-5 weeks
6	Bangladeshi	B Tec	Partner and child	No	No	8 weeks

Appendix 3 – Figure 1

Figure 1: Themes and sub-themes identified from bereaved mothers' interviews

CRedit author statement:

Conceptualisation RG, NA & GR Methodology RG & NA, Software, Validation and analysis RG & NA Investigation, Data curation RG & MG, writing, review and editing RG, NA, GR, MG supervision GR & NA, Funding acquisition GR & NA