Experiences of bereaved parents from South Asian and black communities

Sands

Saving babies' lives. Supporting bereaved families.

East Midlands
Academic Health Science Network
Igniting **Innovation**

The Centre for Ethnic Health Research
national centre for tackling health inequalities

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Executive Summary

The project aimed to explore the experiences of bereaved parents from South Asian and black communities to gain insight into their maternity and neonatal care.

The participants involved in the study had mixed experiences of maternity care services and support offered. They highlighted variation in the quality and safety of maternity services across parts of the system. Participants who received continuity of care and personalised/tailored care, were more likely to report increased satisfaction, greater perceptions of safety, and quality of care.

Most participants wanted a shift to a more holistic approach to care, where the clinical care needs of each pregnant woman are considered alongside their broader circumstances and social needs.

Participants highlighted the diversity within broader ethnic groupings, in particular within black and South Asian communities. Pregnant women need to be seen as individuals and their personal care needs listened to and addressed.

Executive Summary

Topics covered in the discussions

- General experience of maternity care
- Coping strategies post pregnancy loss or the death of their baby
- Cultural responsiveness of health care delivery
- Information and support seeking
- Suggestions for improvement

Background

Every year, thousands of families experience the devastation of pregnancy loss or the death of their baby. In the UK, 13 babies a day are stillborn or die shortly after birth, and it's estimated that more than 1 in 5 pregnancies end in miscarriage.

13 babies

a day are stillborn or die shortly after birth

1 in 5

pregnancies end in miscarriage

A range of factors are associated with a baby being stillborn or dying soon after birth. Each families' risk will be different.

UK data shows that stillbirth and neonatal death rates are higher amongst black and Asian babies compared with white babies, and rates of baby deaths are higher in areas of social deprivation.

For black/black British babies, stillbirth rates are twice as high compared to white babies.

x2

For Asian/Asian British babies it is 1.6 times higher.

x1.6

After birth, the rates of black and Asian babies dying in the first 28 days of life is 1.6x times higher than for white babies.

28 x1.6

Background

Inequalities in baby loss have been known for over 70 years and yet there is a lack of research into why this is the case or what interventions would be effective in addressing this imbalance.

70 YEARS = LITTLE RESEARCH

In this project we spoke with black and South Asian families about their experiences of care around pregnancy, birth and the newborn period to understand whether they think that changes to the way their care was delivered may have made a difference.

No baby should be at higher risk of death simply because of their parents' income, postcode, or ethnicity.

For too long, we have known about inequalities in pregnancy loss and the death of a baby and yet there has been very little progress in reducing these inequalities. Crucially, families who are most likely to be affected by loss have been least likely to be included in research or initiatives to save babies' lives. Without hearing from families themselves about what works for them, the gap will not close.

Project Aims and Objectives:

The project aimed to explore the inequalities in healthcare for South Asian and black communities, by establishing a Public Involvement network to gather evidence on ethnicity-related perinatal mortality.

The project objectives were:

- To shed light on evidence regarding inequality and how it impacts on pregnancy loss and the death of a baby in the black and South Asian communities
- To facilitate culturally-sensitive space for discussion with bereaved parents from South Asian and black communities to gain insight into their experiences of maternity and neonatal care
- To highlight areas for improvement in maternity care management and planning for most disadvantaged groups
- To seek greater understanding of the barriers faced by black and South Asian communities in seeking support after baby loss.

Delivery of Public Involvement Activities

We were particularly interested in seeking input from individuals and groups where the data indicates inequality is most apparent, notably South Asian communities and black African/African Caribbean communities.

Recruitment was carried out by an experienced community outreach and research team who worked with ethnic minority networks, faith groups and community groups to recruit participants.

Given the clear sensitivities for families in talking about a baby death or pregnancy loss, we were careful to approach discussions in an empathetic way.

The aim was to involve a wide range of voices and experiences in these discussions, with a view to identifying and sharing common issues and concerns. We aimed to recruit participants as part of an intersectional approach to engagement, to explore the diversity in lived experience that exists both between and within communities. This included but was not limited to participants of differing protected characteristics (age ranges, gender, ethnic background) in addition to deprivation levels, employment status and health status/disability.

Our approach has built in flexibility to allow for the changing landscape given the COVID-19 pandemic and it was guided by the needs of participants on proposed delivery methods. Both online and in-person options were offered.

The research used group discussions and interviews with women and parents from black and South Asian backgrounds, representing three ethnic minority groups: African, South Asian, and Somali.

Delivery of Public Involvement Activities

In total, the qualitative data was collected from:

- **7 interviews**
- **2 online group sessions facilitated on Zoom**
- **2 face-to-face sessions (based in Leicester and Loughborough)**

The project applied both purposive and snowball recruitment strategies to find and invite the participants.

The participants for the study were recruited through the Centre for Ethnic Health Research and a variety of Sands' channels including:

- through face-to-face (in accordance with COVID-19 rules)
- telephone
- email
- WhatsApp groups
- existing community networks and forums
- voluntary sector, faith organisations
- social media channels

Local organisations, notable Equality Action Loughborough, Bangladesh Youth and Cultural Shomiti, Bangladeshi Youth and Cultural Shomiti in Leicester, as well as Women4Change project were instrumental in supporting the recruitment process.

Participants Characteristics

The total number of participants involved in the project was 25, however, demographic data was only obtained from 19 individuals using an online demographic questionnaire.

Most of the responders were mothers (23). We also spoke with two fathers.

Participants included women who had given birth for the first time and those who have given birth before. Some had given birth some years ago. Most participants were fluent in English, with a small number (2) having limited English language skills. Language support was offered for those women who do not have English as their first language.

The pre-screening questionnaire indicated different types of pregnancy and baby loss amongst participants, including:

Miscarriage before 12 weeks

35% of responders

Late miscarriage
(between 13- 23 weeks of pregnancy)

25% of responders

Stillbirth
(death before birth after 24 weeks of pregnancy)

20% of responders

Neonatal death
(death in the first 28 days of life)

7% of responders

Infant death
(Death between 1 month – 2 years of life)

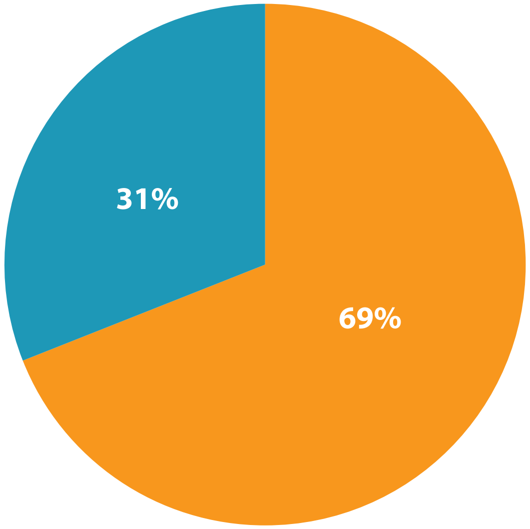
11% of responders

Termination for medical reasons

2% of responders

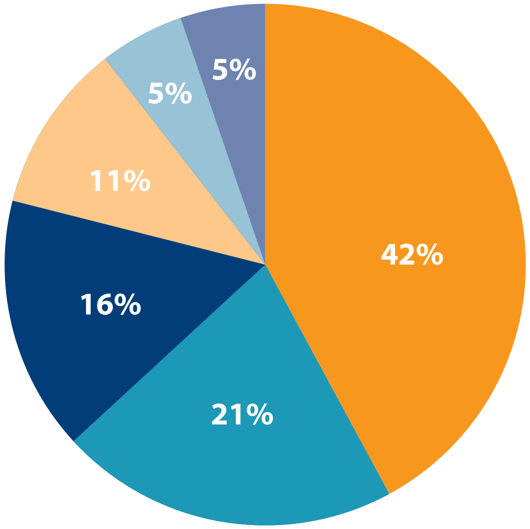
Participants also included women who did not have direct experiences of pregnancy and baby loss; but who were, a close family member or friend who had experienced baby loss, or their baby experienced serious life-threatening complications.

Participants Characteristics



Age

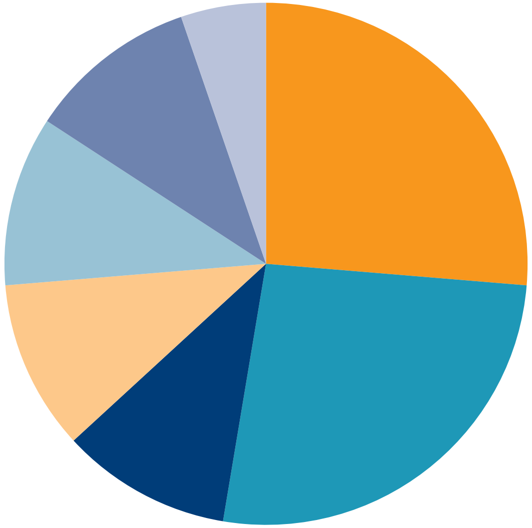
- ■ Women aged between 30 and 44 (69%)
- ■ Women aged between 45 and 59 (31%)



Religion

- ■ Muslim (42%)
- ■ Hindu (21%)
- ■ Christian (16%)
- ■ Sikh (11%)
- ■ Other religion or belief (5%)
- ■ No religion (5%)

Participants Characteristics



Ethnicity

- ■ Bangladeshi (5.26%)
- ■ Indian (5.26%)
- ■ White and black African (2.10%)
- ■ Any other African / Carribean / black background (2.11%)
- ■ African (2.11%)
- ■ Other Asian background (2.11%)
- ■ Pakistani (1.50%)

Main Findings

Quality of care

One of the most common themes black and Asian parents talked to us about was the quality of their care. All too often we heard of experiences where routine checks and procedures were not followed, concerns were dismissed, and bad news was delivered insensitively. We also heard accounts from parents who experienced variability in compassion and the quality of care both within and between different Trusts.

> *"From start to finish it was horrendous, there are so many things... I was dismissed and not seen when I know I should have been. They acted like I was wasting their time. They made me feel foolish."*
>
> bereaved mother

Research tells us that black and Asian women and babies are more likely to experience worse outcomes including death. Families told us how the quality of care they received led to pregnancy loss, the death of their baby or feeling that they were 'lucky' to have a healthy baby not because they received high quality care for complications but in spite of the care they received. Women also spoke about how previous bad experiences with health professionals impacted on their confidence in seeking support.

We also heard about the positive impact that listening and providing choices can make in a difficult situation.

> *"I was amazed at the care and attention they gave; they treated my baby as though she was alive"*
>
> bereaved mother

Main Findings

Parents told us that midwife appointments need to be more meaningful. Parents were aware that health professionals are busy and pushed for time but highlighted the opportunity that midwife appointments can have to build rapport and trust, discuss risks and individual needs and to provide holistic joined up care.

We also heard that parents wanted their concerns to be heard and listened to, staff to have the correct clinical knowledge, bereavement care training to be provided to all staff and for staff to be able to communicate sensitively especially when having difficult conversations. They also wanted staff to be open and honest when things went wrong, to acknowledge their pain and be able to say sorry.

For more information on Sands training visit:
training.sands.org.uk

Some parents also suggested self-advocacy training for black and Asian expectant parents who might not otherwise be able to speak up for themselves or know how to. They explained that they worried about people in their networks who did not speak English, particularly those who would struggle to understand the medical language used in hospitals. They stated that within their networks those who had strong communication skills often spent time supporting others to communicate their needs and articulate themselves in a way that professionals would listen, understand, and act on.

Main Findings

Fathers and Partners

Fathers, partners, and women reported that fathers and partners were often overlooked.

In some situations this was compounded by the pandemic and not being allowed to see their partner or baby.

Fathers told us that in their role they were sidelined and often told to 'be strong' for their partner. This led to feelings of isolation, silently struggling, and limiting access to support for themselves. Fathers also told us that this affected how they grieved and undermined their parenthood.

When seeking support social media was found to be a source of comfort and a place to build community with other bereaved dads. This gave them a space to parent their baby and permission to grieve their death.

> *"Guys don't talk in general, I've found that by opening up on social media it's allowed other dads to find me. They have thanked me for saying things they felt they couldn't. They say they need to be seen to be the strong one."*
>
> bereaved father

Main Findings

Cultural factors, taboo, and stereotyping

Many women received great support from family, friends and people within their community. However some highlighted how cultural factors and taboo played a part in their interactions.

For many, the lack of support and discussion of pregnancy and baby loss within their community was related to cultural taboos. There were different reasons behind this. For example some South Asian women described how older generations see baby loss as a common occurrence and not something parents should be upset about.

IT IS INEVITABLE

Many of the parents we spoke to also believed that taboo played a role in how others responded to them. There was a common belief that their fate was already determined and beyond human control, that the 'loss was inevitable' or 'God sent'.

> *"You do not voice your concerns easily. Women are modest, keep things private. In the Indian community, this topic is hidden under the carpet. Every woman goes through it- so what.??? It is normal, part of your pregnancy journey"*
>
> bereaved mother

Main Findings

Others said that even when people in the community wanted to acknowledge their loss, they did not know what to say or would say the wrong things. Stigma about baby loss and the idea it is a 'private matter' discouraged people from talking about baby bereavement.

In some cases women reported health care professionals were focused on looking for pregnancy conditions more commonly found in their ethnic group, and overlooked the personal health concerns they raised.

The families we spoke to agreed that culturally appropriate care was necessary alongside individualised care. Every pregnancy and baby is different and families should receive care accordingly. Staff should receive training to provide culturally sensitive and person-centered care.

Main Findings

Information & Support

Many of the parents we spoke with said they were aware of the higher risks black and Asian women face in their pregnancy, but they were unsure what that meant for them and how it would impact their pregnancy and baby. They told us they wanted to have open conversations with professionals involved in their care about risk. They felt these conversations could be balanced and honest, gently explaining what to look out for during their pregnancy, when to get help and who to speak to when they were concerned.

Women felt that at times professionals' concerns about causing anxiety meant this information was either withheld or not spoken about.

Women also felt that the way information was given to them during pregnancy was at times overwhelming. They reported being handed leaflets without an explanation of what or why they needed that information. As a result, this was rarely used and people sought information from alternative sources such as Google, friends and family, and their wider networks. Parents also told us about the impact of having unanswered questions which left them with doubts about future pregnancies and babies. Some families spent a significant amount of time researching and learning about their baby's condition, so they were more informed for future pregnancies. Those parents who then did go on to have a subsequent baby after loss reported that the work they

Main Findings

had put in led to having more informed conversations with health professionals about that. They wished that they had been given that information during their previous pregnancy as it may have helped prevent the loss.

> *"Pregnancy is a worrying time for any mother who is expecting; support offered at the beginning is so important, you feel alone. You need support. You need reassurance. At that time, I felt unsupported, unwelcomed to access the system, ask questions. You don't know any of the reasons behind your loss, you are blaming yourself. You need reassurance. You turn to your friends and families to seek these answers and reassurance".*
>
> bereaved mother

Parents also felt that when they were given bad news this should have been accompanied by psychological support and practical information about next steps. They felt that this didn't always happen.

The women wanted to know about the risks associated with procedures even when there were few alternative treatment options.

For some women the lack of information has meant that they still have unanswered questions about how procedures during pregnancy or birth are impacting their current health. It was also suggested that psychological support continues after parents have left hospital or there is a handover to a support organisation. Some parents said they were not provided with information about where to get help and if they were, it was often a leaflet within a memory box which some parents found difficult to open so soon after their loss. Parents often sought this information out for themselves, many reported that they did get good support from their network or friends and family.

Conclusion

This project has shown that to improve outcomes for black and South Asian communities care should consider the holistic needs as well as clinical needs of mothers, parents and families.

Drawing on the evidence collected, the overarching theme from the discussions suggests the need for greater emphasis on providing a more holistic approach to care. It is important to address the workplace pressures faced by healthcare professionals to enable this (in particular, staff training and risk assessment procedures).

Sub-themes highlighted the need for ongoing support and reassurance to those women who have experienced baby loss or miscarriage. Failure to listen to the needs of women can negatively impact on the safety of maternity care and outcomes. Addressing inequalities for black and minority ethnic groups who have continued to experience poorer outcomes is essential to avoid perpetuating and aggravating existing disparities.

For more support information visit: sands.org.uk/support

Acknowledgements

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