

SOCIAL NETWORKS AND INFANT MORTALITY: KEY FINDINGS

ABOUT THE STUDY

UK rates of infant mortality for mothers born in the Caribbean, Africa and Pakistan, and for teenage mothers are considerably higher than the national rate (ONS 2013) and social exclusion is linked to inequalities in infant mortality. Risk reduction strategies include addressing environmental stressors, improved services and increased social support for women at risk (DH 2007).

It is known that the quality and type of support that women receive during maternity significantly affects their health outcomes (Austerberry et al 2007; Sosa et al 1990; Oakley et al, 1994). Ethnic inequalities in maternal health have been linked to substandard care (Knight et al. 2009) and higher spending on maternity services is unlikely to reduce rates of infant mortality unless services are tailored to the needs of the populations they serve (Freemantle et al. 2009).

Being well connected gives access to material and informational resources that can improve health (Gayen and Raeside 2007). This study sought to explore the nature of social networks for maternal and child health for women from diverse

communities. Findings highlight the extent to which relationships within women's networks support maternal and child health and empower pregnant women. The study also provides evidence about the kind of interventions that are suggested by women who have experienced an infant death and how effectively these can be translated into practice.

The study was conducted at two sites in the North of England with higher rates of infant mortality than the national average. Evidence was gathered through: a review of relevant literature; secondary analysis of national data; qualitative interviews with 10 key policy and practice actors at each site; qualitative interviews with bereaved and non-bereaved women and participatory research activity. An advisory group of healthcare providers, academics, maternity service users and individuals involved in commissioning oversaw the study.

Researchers interviewed 23 women from African, Pakistani or teenage backgrounds who had experienced an infant death as well as 26 women from a range of ethnic backgrounds and ages who had felt well supported throughout pregnancy and up to the first year of their child's life. Interviews explored links between women and contacts in their personal networks who provided support during pregnancy and following birth. Both narrative and participatory research methods were linked with qualitative and Social Network Analysis. We analysed how women constructed their networks and the quality of relationships within these as well as the influence of socio-economic position, age, ethnicity and religious identity on maternity support that women received.

An empowering model of participatory research was adopted and Project Development Groups made up of bereaved women at each site were set up. Group members had training and support to develop ideas about service changes that were needed, and to engage with key local professionals. The women were involved in presenting findings about gaps in support at two developmental workshops held to stimulate service development. An evaluation of this participatory work was conducted at the end of the study. Dissemination activities involved group members in conference, workshop and media presentations as well as writing up findings from the participatory phase.

FINDINGS

Perceptions and management of risk

- A range of risk factors involving individual, biological and social issues were identified. Prematurity, low birth weight and deprivation affected all three groups.

Rates of infant death compared to national rate (4.2 per 1000):

	<u>Rate</u>	<u>Higher by</u>
Caribbean mothers	(9.7)	131%
Pakistani mothers	(7.6)	81%
W. African mothers	(7.4)	76%
Teenage mothers	(5.4)	29%

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- Bereaved women and their families often had poor knowledge of pregnancy complications and could delay reporting warning signs. Professionals often organised extra appointments, scans or admission to hospital in response to women's concerns, however, a number of minority ethnic bereaved women complained their concerns were not taken seriously, particularly in relation to labour admissions. The higher risk of prematurity in these groups did not appear to influence admission procedures; findings indicate a need for more sensitivity to warning signs such as bleeding, reduced foetal movement and pain in these two groups.
- Bereaved women described uncertainty and a high level of reliance on professional advice, for first pregnancies in particular. A number of women felt they had been failed by professionals who undermined their concerns until a crisis had been reached. Missed opportunities to intervene effectively could occur in both primary and secondary care settings.
- A considerable disconnect existed, particularly at Site B, between the experiences bereaved women described and key informants' descriptions of risk factors. Some key informants focused heavily on issues external to maternity services, such as deprivation and genetic causes.
- Parents' views about causation were not explored at either site as part of local reviews of infant deaths. Women's concerns about delays in admission during labour or other problems with care were therefore unlikely to be picked up in ways that could inform service development
- Specialist Teenage Pregnancy Midwives and the national Family Nurse Partnership offered long-term continuity of care, joined up provision and a high quality programme of support tailored to the individual needs of teenage mothers at highest risk. This level of support was not routinely available to Pakistani and African women and there was considerable potential to transfer aspects of this model of targeted provision to women who are at even higher risk of infant death.
- The implementation of NICE guidance (2010) in relation to pregnancy and complex social factors was lacking at both sites. The guidance highlights the need to commission dedicated staff; establish routine interpreting and coordinated care; joint training between agencies; and service development based on feedback about women's satisfaction with services, gathered at antenatal appointments.
- Lack of language support could distress mothers at times when they were most vulnerable, some had to interpret for their husbands whilst being given news of their child's illness or death.
- There was little or no representation of women from the three higher risk groups in decision-making structures about maternity or child health services and no mechanisms to gain feedback from them. In addition, staff in maternity services did not represent the populations they served. Pockets of prejudice were felt by some respondents to affect the quality of support provided. We found no clear strategy to address this lack of diversity in mainstream settings.
- Staff from minority ethnic backgrounds who were employed in mainstream settings sometimes referred to feelings of exclusion and marginalisation which mirrored the feelings

“I couldn't feel her moving so we put that down to because it's a girl and she's lazy. That's what my husband said, 'Oh it's a girl, look she's lazy...”

Bereaved Pakistani mother

“I said 'look, I'm in a lot of pain and I think probably my waters have broken ... I didn't feel that they took me seriously. They just advised me to manage it and to watch it”

Bereaved African mother

“I met new people here and through these people, I found more groups ... she did loads for me ... I had loads of trips with them for mums, like groups. It was really good... I think they should have more family nurses about”

Non bereaved White British teenager

“I've sat in meetings where I'll listen to people's kind of prejudices about certain groups – you know 'living off the state'... 'living on benefits'... 'having all these children'...you know – 'you keep sending them appointments and they don't turn up' and that...there's a lot of blame isn't there?”

Key Informant: Children's Services manager

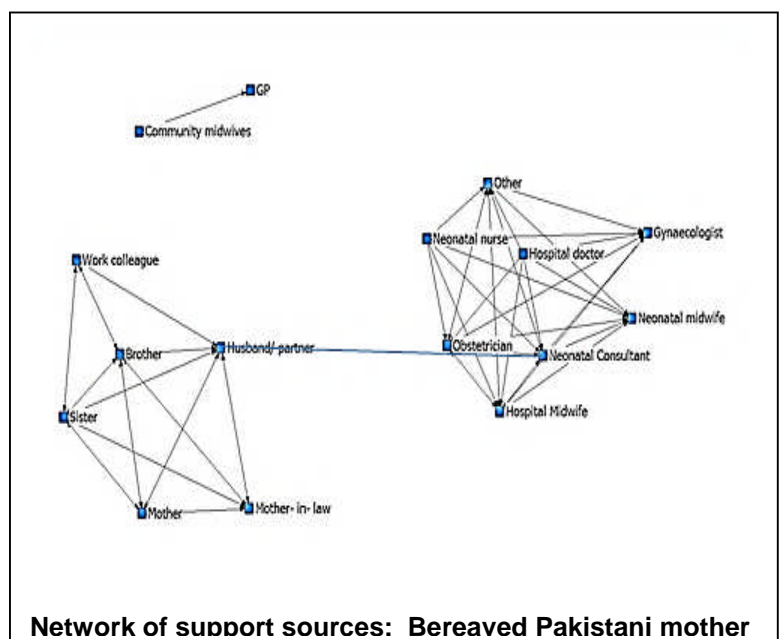
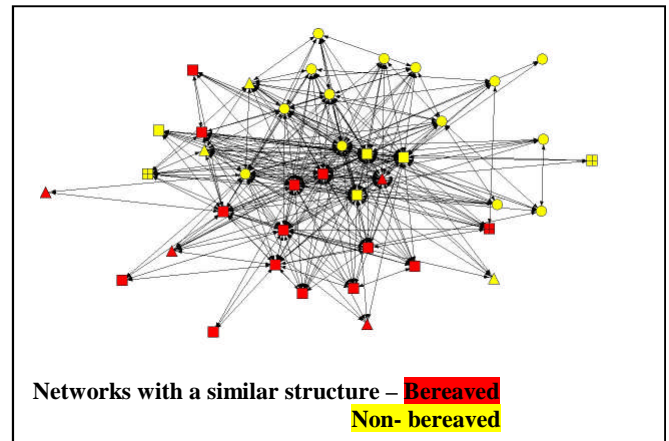
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described by bereaved mothers. Findings suggest a need for greater leadership and prominence in valuing and promoting staff diversity within maternity services.

- Despite evidence of multifactorial explanations for the higher risk of infant mortality affecting Pakistani mothers, only congenital anomalies received significant policy and research attention, particularly at Site B. The focus on difference alone meant that deprivation and prematurity in this population were not given adequate policy attention.
- Community campaigns to raise awareness of genetic risk linked to cousin marriages did not increase access to support for consanguineous couples. Findings suggest that interventions to increase (i) access to genetic screening and (ii) counselling for affected families are needed.

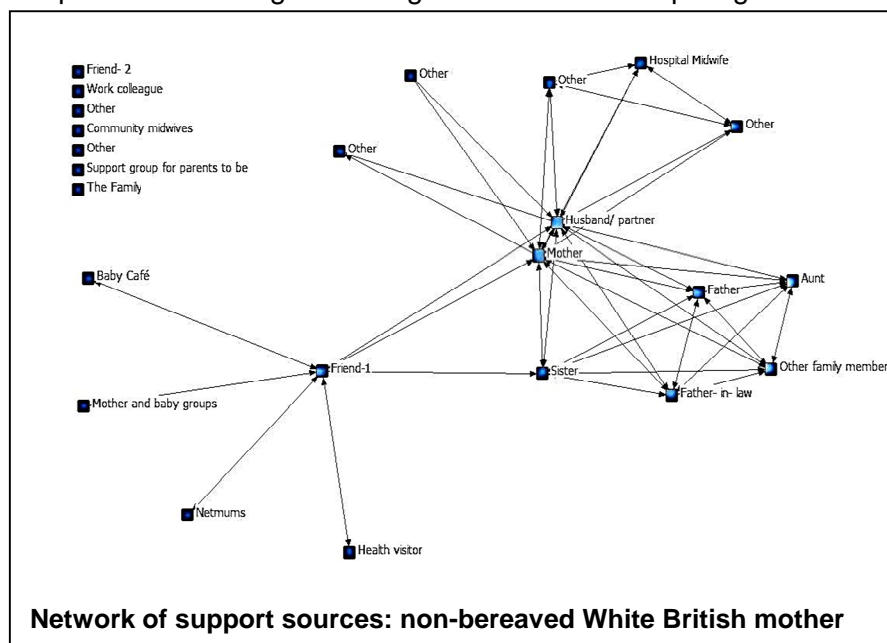
Sources and levels of support

- Over 80 potential sources of support were identified during the course of the study linked to family or personal networks, Community, Primary and Secondary healthcare, Local Authority and voluntary sector services as well as online websites and discussion groups.
- Findings suggest a lower priority in terms of provision to meet the needs of women from minority ethnic backgrounds as compared to teenagers. This was particularly noticeable at one of the sites involved in the study, where more than half of births were to women from BME backgrounds.
- Many bereaved women, whether teenagers from White British backgrounds, Pakistani or African mothers, had networks that were similar in structure to each other and the same applied to many White British, Pakistani or teenage mothers who were non-bereaved.
- Non-bereaved women tended to name more contacts in their networks than bereaved women despite having fewer health needs. Non-bereaved women had often proactively developed new sources of maternity support via local authority, specialist or voluntary sector services, whereas bereaved women accessed these services far less often.
- Bereaved women had networks of support that were more tightly knit than those of non-bereaved women and that contained a narrower range of contacts. The lack of new connections relating to pregnancy meant that bereaved women were far more dependent on primary care professionals to develop knowledge and support specific to maternity, rather than accessing this from a wider range of sources
- In terms of personal networks, non-bereaved women gave slightly higher average scores for Husband/Partner, Mother and Father but scored closest Friend more highly than any other actor. Sister and Brother appeared to be more common sources of support for bereaved mothers. Non-bereaved women rated GPs, midwives and health visitors more highly on average than bereaved women did in terms of support and contribution to wellbeing.



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- There was a complex relationship between ethnicity, age and deprivation as Pakistani women and teenage mothers are both overrepresented in deprived areas. Deprived women tended to have more connections between actors in their network than more affluent women. A strong personal support network could mean that Pakistani women might not perceive a need to seek out alternative sources of support and professionals might also regard them as not requiring additional support.
- White British and Pakistani mothers both usually had a tightly knit component of personal support within their network. However, White British women were more likely to have a range of other support sources that were not in touch with each other, giving them the ability to weigh advice from different sources and take up the support they felt was most valuable to them.
- Pakistani women were less likely to access antenatal groups as they often felt they already had access to the emotional support and tailored advice that White British women sought out from these groups. Encouragement to attend could be helpful if women had misconceptions or concerns about these groups. However, bereaved women who had used antenatal classes felt these had not prepared them to recognise warning signs for the complications they experienced.
- Interventions likely to improve access to information and support for women at higher risk are: (i) supporting women to build a broader range of support sources linked to maternity, beyond their immediate family and friends and (ii) increasing knowledge about risk factors amongst such women and the professionals who support them.



Relationships within women's networks

- Women rated personal contacts much more highly than professionals in terms of overall contribution to wellbeing. Women often received emotional, practical and decision-making support from family, friends and professionals as well as help to increase confidence and deal with challenges. Not all personal or professional contacts were supportive, however, and women sometimes described ambivalent or negative relationships with both types of contacts in their networks.
- Many White British non-bereaved women reported deliberately developing their support networks during and following pregnancy to fill perceived gaps in knowledge and emotional support. They often sought out certain attributes in the friends they made such as shared values and preferences for parenting and working patterns. Some described their friendship group as a "tribe", suggesting a role in maintaining or shaping identity, and the friendship group was often a key source of informational and emotional support, as well as advocacy (see quote).
- Whilst bereaved women were more likely to trust their sisters for maternity support than non-bereaved women, they reported less support that enhanced their confidence from sisters and friends. Friendships among the bereaved group

“they made it really great and we were singing from a similar hymn sheet. [...] we all wanted to be well informed and we all wanted to know what all the different options were, we were interested in all different sides and none of us had this attitude of: the midwife and health visitor will tell us what to do and that is it.”

Non bereaved White British mother

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tended to precede the pregnancy whereas it was common for non-bereaved women to establish new friendships through support networks linked to the experience of having a baby.

- Bereaved women rated their own social status and the status of everyone in their network lower than non-bereaved women. They also felt their own social position was much lower than professionals in maternity services, whereas non bereaved women on average felt their status was closer to that of midwives and health visitors.
- Professionals' contribution to wellbeing was lower across both groups, but the most striking difference between the groups was for hospital midwife, where non bereaved women's average ranking was 6/10 whereas it was only 4/10 for the bereaved group. Primary care professionals were also scored more highly by non-bereaved women. Non-bereaved women were more likely than bereaved women to say they had received emotional support from professionals.
- The positive aspects of professional support which women valued included emotional support, empowerment, encouragement and reassurance, professionalism and trust, practical and information support and support in making decisions. Women appreciated staff who tailored advice and support to them, not just giving "textbook" answers. Continuity of personnel made such support more likely and easily accessible staff members were also highly valued.
- Many women were aware of constraints in terms of staffing numbers and were very appreciative of any practical help they did receive, such as with infant care, in particular while in hospital in the postnatal period. Women and their families employed strategies to access the support they were seeking, whether through being consciously aware of their own manner and responses, remaining positive, or learning to speak up and ask for help and be assertive of their needs.
- Negative experiences of support from professionals included the impact of overstretched services. Some women, in particular from the bereaved group, reported difficulties in asking for help or asserting needs, Many women, more usually in the bereaved group, also reported a lack of empathy from staff, and described feeling vulnerable during the birthing process. Some reported unfriendly or even a hostile manner from staff, with examples of discriminatory comments.
- Where a relationship of trust was not established, women reported feeling unable to ask questions and did not have access to additional resources which may have been lacking in their own personal networks, such as information support. Such experiences are likely to have also maintained or increased anxiety and mistrust of available support groups. Improved ethnic mix of staff, culturally appropriate provision and more widespread use of interpreters were highlighted as improvements which would make a big difference.

“Nobody says to you: ‘how are you managing? Are you coping? Are there any questions you want to ask? Is there anything you are having problems with? You know there is this, this and this support out there...’ Nobody has got two minutes to spare to stop and say that to you. That’s the most important thing in the whole process. And they haven’t got time for that.”

Bereaved Pakistani mother

Supporting women to have a voice

- Of the 23 bereaved women who took part in the study, 10 took part in in the participatory phase, four at site A and six at site B. Women were keen to meet regularly as the ‘HOPE’ groups, motivated by the desire to make a difference for other women and families in the future and also for mutual support.
- The HOPE groups identified key priorities for action and produced documents outlining their ideas for what would help. Key priorities were identified in the areas of relationships, knowledge and service design. Women at both sites wanted to be listened to and taken seriously by professionals, not to feel judged or stereotyped and to have access to more bereavement support. In

“Whatever we’ve tried to say they’ve actually tried to make it happen, listening to us and taking it further which we couldn’t have done on our own”

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addition, being better informed about warning signs and having honest, clear and complete information were seen as priorities for improving knowledge. In terms of service design, women at both sites wanted more involvement in decisions around how services are run. At Site B, better interpreting provision, more resources in other languages, a better ethnic mix of staff and targeted support for women most at risk were additional priority areas.

- Inclusion of a group member who faced child protection issues was particularly challenging and researchers experienced pressure to replicate her previous experience of exclusion and not being heard.
- Training needs in communication and listening skills were identified and some training was provided. Researchers and trainers also worked with the groups to help make meetings more effective and encourage everyone's contribution. Where opportunities to speak about the women's ideas arose, such as radio interviews and conference presentations, the researchers sought to involve women. Seven HOPE members presented their personal experiences at a conference in Northern Ireland alongside the researchers, who linked the stories to findings from the study.
- At both sites, HOPE members formed links with the Maternity Services Liaison Committee, although women had mixed experiences of meetings. At Site A, members got involved in an MSLC subgroup to improve bereavement support at the local hospital trust. They also worked with Public Health to tailor antenatal education material for women in higher risk groups. At Site B, a health visiting/ midwifery pathway for women at higher risk was developed and also a neonatal service user forum.
- Workshops were held at both sites to encourage more of this kind of activity. These were well attended by local practitioners and policymakers and HOPE members presented with researchers again. Further initiatives on interpreting provision, staff diversity and identifying women at higher risk in delivery suite triage were developed, as well as a range of other actions.
- Bereaved women's perspectives could sometimes be hard for professionals to hear, but those who did engage focused on drawing out lessons and on solutions rather than taking criticism personally.
- Evaluation of the participatory phase showed that women who took part appreciated the opportunity to be more involved in the research, and all felt more powerful as a result. All felt that they had been able to have a say in developing the aims and direction of the work. The conference in Northern Ireland and the developmental workshops were felt to have been very successful and worthwhile. There were mixed feelings at Site A, where some women were frustrated that change was slow to happen and that more had not been achieved. Women at Site B were more satisfied with the outcomes they had been able to achieve and with emotional support available to them, mainly because of differences in the way local practitioners engaged with the groups at each site.
- At both sites, women wanted to continue meeting after the research ended. This was raised at the workshops and support to continue was offered by Public Health partners working on infant mortality at Site A and by the National Childbirth Trust at Site B.
- Participatory methods are an empowering way of helping women at higher risk of infant death to have a voice in how health and social care services are run. This study has shown that groups like HOPE are feasible and can have a considerable impact on service development.

“A bit of money, a bit of support can go a long way and it would be nice to see other people learning from this”

Further details of this project are available at these University of Leeds and ESRC websites:
http://medhealth.leeds.ac.uk/info/615/research/352/social_networks_and_infant_mortality
<http://www.esrc.ac.uk/my-esrc/grants/RES-061-25-0509/read>

A full report of findings will be made available on these websites by December 2013.

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