Infant Mortality and Pakistani communities: Social, genetic or what?

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Background

• Social exclusion and inequalities in infant mortality
• UK rates of infant mortality for mothers born in Pakistan, the Caribbean and teenage mothers are 100%, 63% and 60% higher than the national rate respectively
• Risk reduction strategies suggested include optimising maternal and mental health and addressing environmental stressors (DH 2007), improved services and increased social support for women at risk
Plan of investigation

Four phases:

• Explore the current evidence, policy guidance and local context (Leeds and Bradford).

• Recruit and interview women from a range of backgrounds in two matched groups (30 at each site) who have
  (i) experienced an infant death
  (ii) a child over one year old

• Analyse data using quantitative and qualitative methods.

• Project development group aimed at finding solutions to the problems identified using participatory research methods
Workshop Outline

• Review of infant mortality policy with reference to ethnicity
• Review of evidence for impact of pre and post natal social support on birth outcomes
• Data from key informant interviews
• Questions for group discussion
National Infant Mortality Policy and Ethnicity

- Infant Mortality as a component of NHS plan (2000)
- 2002 National Health Inequalities PSA target and infant mortality action plan a key part of public health strategy
- Main focus of target is socio-economic inequality
- However, recognition within 2007 Dept of Health review of target that certain groups such as women born in Pakistan have significantly higher risk
Scarf Diagram

What would work

<table>
<thead>
<tr>
<th>Action</th>
<th>Impact on 2002-04 gap (percentage points)</th>
<th>Actions/interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reducing conceptions in under-18s in the R&amp;M group by 44% to meet the 2010 target</td>
<td>1.0</td>
<td>Targeted prevention work with at-risk teenagers and targeted support for pregnant teenagers and teenage parents</td>
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<tr>
<td>Reducing overcrowding in the R&amp;M group, through its effect on SUDI</td>
<td>1.4</td>
<td>Increase the supply of new social housing; pilot innovative approaches to making temporary social stock permanent; encourage better use of housing stock</td>
</tr>
<tr>
<td>Targeted interventions to prevent SUDI by 10% in the R&amp;M group</td>
<td>1.4</td>
<td>Maintain current information given to mothers and target the Back to Sleep campaign and key messages to the target group</td>
</tr>
<tr>
<td>Reducing rate of smoking in pregnancy by 2 percentage points by 2010</td>
<td>2.0</td>
<td>Smoking cessation as an integral part of service delivery for the whole family during and after pregnancy</td>
</tr>
<tr>
<td>Reducing the prevalence of obesity in the R&amp;M group to 23%</td>
<td>2.8</td>
<td>Support the contribution LAAs can make to tackling obesity; develop plans to implement NICE obesity guidance with a focus on disadvantaged groups</td>
</tr>
<tr>
<td>Meeting the child poverty strategy</td>
<td>3.0</td>
<td>Develop plans to help women with a BMI of over 30 to lose weight by providing a structured programme of support</td>
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Immediate actions
- Optimising preconception care
- Early booking
- Access to culturally sensitive healthcare
- Reducing infant and maternal infections

Long-term actions
- Improving infant nutrition
- Improving maternal educational attainment

Provide comprehensive preconception services
- Provide advice/support for at-risk groups within the target group, e.g. BME groups
- Increase direct access to community midwives
- Provide 24/7 maternity direct line for advice and access
- Implement NICE antenatal and postnatal guidelines
- Health equity audit of women booked by 12 weeks and more than 22 weeks gestation
- Commissioners and maternity service providers agree improvement plans in contract
- Improve uptake of immunisations in deprived populations
- Implement Baby Friendly standard
Scarf diagram: key focus of national and local policy

- National policy centred around actions modelled in the Scarf diagram, a modelling of 7 interventions targeting R&M group
- Significant impact on shaping of local policy
- Interventions may have an impact on some of the risk factors for teenage mothers in particular
- Arguably don’t directly address issues facing women of other high risk groups
- Risk of perpetuating inequality in infant mortality for those at highest risk
• Recognition within DoH review of significance of interplay between poverty and ethnicity
• Yet not reflected in key targets as outlined in scarf diagram
• Genetics service in Blackburn given as good practice example, among other case studies
• Risk of obscuring significance of complex interaction of socioeconomic status and other factors around access to care in causal pathways for IM
Existing evidence

Evidence for complexity within explanations of variations in infant mortality:

• 4% of consanguineous couples have a child with a congenital abnormality compared to 2% otherwise (Modell and Darr 2002)
• Rates of terminations for an anomaly vary among different ethnic and socioeconomic groups
• Socio-economic status as a key risk factor for infant mortality, closely intertwined with ethnicity
• Support available to women also linked to higher rates of infant death
Evidence for significance of quality and type of support accessible to women and families pre- and post-natally

Health outcomes for mothers and infants influenced by

- presence of a birth companion (Sosa et al 1990)
- quality and type of social support from partner, family and friends (Austerberry et al 2007)
- connectedness in social network- facilitating access to material and informational resources, but network may reflect poverty and disadvantage/lack of resources (Gayen and Raeside 2007)
- Perceived **quality** of support from all sources more impactful on health outcomes, not frequency of support (Oakley et al, 1994)
NPEU survey of women’s experience of maternity care (2010) found:
- later booking for women from minority ethnic groups (which may result in inequalities in prenatal testing (Smith et al, 2011))
- less awareness of choices around maternity care
- less trust and confidence in staff

Health Care Commission review of maternity services (2008): women from minority ethnic groups more likely to be left alone during labour and report feeling worried by this, an example of discrimination within healthcare contexts

Recognition from health care professionals of training needs such as in effective communication, and skill gaps beyond dealing with particular issues such as sickle cell anaemia (Chevannes 2002)
• Complex area with lots of uncertainty (Kurinczuk 2010)
  – Congenital anomalies contribute about one third of the extra infant deaths in routine and manual groups
  – 4 x higher risk of infant death from CA in Pakistani babies
  – underlying cause most often not known
  – not always possible to offer genetic screening

• Inequalities between socioeconomic and ethnic groups for 9 fatal anomalies disappear when terminations taken into account (Smith et al 2011)
  – Lower rates of termination amongst Pakistani women not taken into account in infant mortality figures
  – But rare conditions may not be covered by the anomalies investigated
Key Informant Interviews: Ethnicity and risk

- Deprivation (lbw), prematurity, communication barriers, genetic risk/terminations, quality of healthcare, health literacy, confidence and capacity to seek support
- Good practice **adaptations** to meet needs but **not routine or embedded** within mainstream services:
  - Haamla, Choto Moni, Mothers in Exile, Maternity Outreach Volunteers
  - Bradford Doulas, Genetics training/campaign
- **Ethnicity not a trigger** to explore related risk factors despite higher rates of infant mortality
Ethnicity and network relationships

Staff shortages/pressures/dynamics within teams

Staff in mainstream services not representative of minority ethnic communities - impact on relationships

- Ability to respond, lack of empathy - ‘task-based’ rather than caring relationships
- Interactions influenced by perceptions of group identity/stereotypes and what people ‘think they know’/‘instincts’:

“it’s very like when you read accounts of Britain in Victorian times, that, you know, the woman was the last person to eat in the family. She makes sure the children eat, her husband eats, that they’re all sorted, and then, if she’s got time, she thinks of herself”
Consanguinity perceived as a ‘sensitive area’, ‘inherently dangerous’ and major explanatory factor

Reduced credibility of those who suggest a more complex perspective - ‘in denial’; ‘minimiser’; ‘not an expert’. Different positions seen as a ‘cultural divide’

Genetic awareness a part-solution: clearer pathways needed for better access to genetic counselling for individuals/affected families - ‘primary prevention’.

Termination after diagnosis of CA a moral decision with consequences for well being of woman and child – need for broader service responses to these decisions
• Research role in Family Nurse Partnership programme - exclusion of young BME women with language needs and risk factors not explored if with family (migration, isolation, deprivation, access)

• Parallel intervention suggested for BME women – ie targeted programme of comprehensive support

• Lack of local research a reason for lack of local action (cf teenage pregnancy pathway).

• Feedback mechanisms for service development underrepresent BME women
Religion and ‘risk factors’

• **Supportive**: eg Muslim chaplains/religious authorities supporting breastfeeding advice; mosques disseminating health promotion materials.

• **Supporting women/conflicting with professionals**: Some religious authorities perceived to be ‘in denial’ about genetic explanations for infant mortality. Muslim staff seen as ‘dissuading’ post mortems considered ‘very important indeed’ by doctors re potential for informing about future pregnancies. Religious teachings on terminations

• **Stereotypes/prejudicial views** of Islam may be promoted amongst professional actors – influenced by ethnic and social class as well as religious differences. Professional relationship with individual women may be influenced by their perception of women’s social identity before interaction has even taken place
Conclusion

• Importance of a broader approach, responsive to specifics of local context
• Design and delivery of a genetics service must be tailored to local situations, needs and perspectives
• Vital to address challenges in delivering health care and support to women and families from minority ethnic groups
• These challenges are likely to play out in the delivery of a genetics service and could threaten its success
What should a strategy for reducing infant mortality in the Pakistani community look like?

How might this address:

- deprivation: low birth weight, prematurity
- access to support
- genetic risk factors/termination decisions
- quality of healthcare
- specialist support services?
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