Improving Care in Pregnancies After Stillbirth – Evaluating The Rainbow Clinic

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St Mary’s Hospital
Rainbow Clinic

2013
• St Mary’s clinic (RC)

2016
• Wythenshawe clinic (WRC)

2018
• Royal Berkshire (RBH)

Risk factors and Stillbirth

The majority of stillbirths occur in women with no apparent risk factors (81%)

• Majority confer moderately increased risk
  – Advanced maternal age (>40) (1.6 - 3.6x)
  – Diabetes (2.7x), Hypertension (2.0x)
  – Cigarette smoking (1.3-1.6x), Alcohol >5u/wk (2-3x)
  – Reduced Fetal Movements (2-3x)
  – Small for Gestational Age (19.8x)
  – Previous Stillbirth (2-10x)
  – Meta-analysis 4.7x Lamont et al. BMJ 2015

Complications in subsequent pregnancy

- Black et al. *BJOG* 2008
- Grampian region of Scotland
- Women with prior SB (n = 364) & live birth (n = 33,715)
- Women with previous SB
  - Increased risk of pre-eclampsia (OR 3.1, 95% CI 1.7-5.7)
  - Prematurity (OR 2.8, 95% CI 1.9-4.2)
  - Low birthweight (OR 2.8, 95% CI 1.7-4.5)
  - Placental abruption (OR 9.4, 95% CI 4.5-19.7)
  - Induction of labour (OR 3.2, 95% CI 2.4-4.2)

What are women’s experiences in subsequent pregnancies?

*Parents’ experiences and expectations of care in pregnancy after stillbirth or neonatal death: a metasynthesis*

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Accepted 6 December 2013. Published Online 4 March 2014.

Background Pregnancy after perinatal death is characterised by:
Main results Fourteen studies were included in the synthesis,
Care in Pregnancies After Stillbirth – International HIC Perspective

- Wojcieszek et al. BJOG 2016 - 2716 parents, from 40 high- and middle-income countries
- The majority (66%) of parents conceived within 1 year
- Large variation in care, but additional antenatal visits/scans were provided for 67% and 70% of all parents.
- Care addressing psychosocial needs less frequent.
- Parents whose stillbirth occurred ≥ 30 weeks more likely to receive additional care, particularly the option for early delivery after 37 weeks.
- 47–63% of all parents felt elements of quality, respectful care were consistently applied, e.g spending time with parents and involvement in decision-making.

Table 4. Quality, respectful care overall and by geographic region

<table>
<thead>
<tr>
<th>Region</th>
<th>Total (n = 2716)</th>
<th>Oceania (n = 336)</th>
<th>Western Europe (n = 200)</th>
<th>Southern Europe (n = 488)</th>
<th>Northern Europe (n = 245)</th>
<th>Latin America (n = 371)</th>
<th>North America (n = 250)</th>
<th>UK and Ireland (n = 526)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you given the information you needed?</td>
<td>1310 (48.2)</td>
<td>173 (51.8)</td>
<td>140 (53.8)</td>
<td>267 (41)</td>
<td>131 (54.4)</td>
<td>173 (46.6)</td>
<td>179 (61.1)</td>
<td>279 (54.5)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>801 (29.5)</td>
<td>103 (30.8)</td>
<td>83 (32.1)</td>
<td>140 (27.4)</td>
<td>78 (32.6)</td>
<td>103 (27.0)</td>
<td>71 (24.2)</td>
<td>174 (33.1)</td>
</tr>
</tbody>
</table>

Did your care providers spend enough time with you?

| Always | 1391 (51.2) | 184 (55.1) | 166 (68.8) | 282 (41) | 136 (52.8) | 188 (48.5) | 177 (50.4) | 239 (46.4) |
| Most of the time | 691 (25.6) | 85 (25.4) | 65 (25.0) | 183 (36.6) | 62 (25.7) | 88 (23.7) | 61 (20.8) | 147 (27.8) |

Did your care providers talk to you in a way you could understand?

| Always | 1622 (59.7) | 203 (60.8) | 175 (68.5) | 311 (53) | 166 (68.9) | 201 (54.2) | 217 (64.1) | 303 (57.6) |
| Most of the time | 683 (25.1) | 96 (28.6) | 60 (23.1) | 201 (39.3) | 56 (23.3) | 87 (23.5) | 52 (17.7) | 137 (26.0) |

Did your care providers listen to you?

| Always | 1443 (53.1) | 195 (58.8) | 166 (63.8) | 297 (43.2) | 145 (60.3) | 177 (47.7) | 203 (65.3) | 258 (49) |
| Most of the time | 640 (23.6) | 79 (23.7) | 51 (19.6) | 172 (27.5) | 62 (25.7) | 83 (22.6) | 50 (17.1) | 143 (27.2) |

Did your care providers take your concerns seriously?

| Always | 1441 (53.1) | 196 (58.7) | 164 (63.1) | 299 (42) | 148 (61.4) | 181 (48.5) | 191 (65.2) | 269 (51.1) |
| Most of the time | 601 (22.1) | 69 (20.7) | 50 (19.2) | 172 (27.5) | 56 (23.2) | 74 (19.9) | 56 (19.1) | 124 (23.6) |

Did your care providers treat you with kindness and respect?

| Always | 1714 (63.1) | 220 (65.8) | 187 (71.8) | 316 (54.7) | 171 (71) | 224 (60.6) | 226 (77.1) | 308 (58.6) |
| Most of the time | 580 (21.4) | 75 (23.1) | 43 (16.6) | 168 (24.4) | 49 (20.3) | 71 (18.1) | 46 (15.2) | 121 (23.1) |

Data for “Other” geographic region (n = 5) not shown in regional breakdown.

Wojcieszek et al. BJOG 2016
Important Aspects of Care for Parents

What do you feel is the most important aspect of care in #PAL #babylosshour

- Specialist scans: 43%
- Named Midwife: 32%
- Antenatal checks as/when: 20%
- Logo on notes: 5%

44 votes · Final results

Clinical Care After Stillbirth

- Diagnosis
- Induction of Labour
- Complications during birth
- Investigations
- Bereavement Support
- Preconception Care
- Care in Subsequent Pregnancy
What is Rainbow Clinic?

• Multidisciplinary Specialist antenatal service
• Consultant Led
  • Additional midwifery Support (Research MW/MUP & Bereavement MW)
  • Continuity of Care/Carers
  • Directed investigations
• Women seen at 23 weeks for placental profile scan
• Shared care with relevant services
  • Diabetes / Hypertension Clinic

Referral Criteria

Previous stillbirth after 24 weeks (including multiple stillbirths)

Previous fetal death in utero between 20-24 weeks

Previous neonatal death due to placental cause (up to 28 days of age)
Care in Subsequent Pregnancy

Review History
Appropriate Intervention
Anomaly Scan
Placental Profile
Growth/Doppler scans
Awareness of Risks + Support
Plan birth

10+6 weeks
17 weeks
23 weeks
28 weeks

International Consensus Statement
• Jointly led by a team from Toronto and Manchester
• Wider multidisciplinary group of 27 professionals and parents
• Initial workshop in 2015, statement refined and developed over 3-year period, published in 2018
• Published by SOGC
• Endorsed by International Stillbirth Alliance
The role of aspirin, heparin, and other interventions in the prevention and treatment of fetal growth restriction

“A 100-150mg evening dose of aspirin commenced prior to 19 weeks’ gestation provides a modest risk reduction in women at risk using conventional obstetric history-based risk factors”
Compassionate Care for birth

Outcome Data

• Preterm birth rate has remained lower than before Rainbow Clinic (15% vs. 21%)
• High Caesarean section rate (dependent on previous IPSB)
• NICU admission reducing in frequency

<table>
<thead>
<tr>
<th>Year</th>
<th>Period</th>
<th>Births &lt;37w (%)</th>
<th>IOL (%)</th>
<th>El CS (%)</th>
<th>Em CS (%)</th>
<th>SVD (%)</th>
<th>Instrumental Delivery (%)</th>
<th>NICU (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016</td>
<td>Q1</td>
<td>0</td>
<td>41.7</td>
<td>20.7</td>
<td>37.9</td>
<td>37.9</td>
<td>3.4</td>
<td>17.2</td>
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<tr>
<td></td>
<td>Q2</td>
<td>18.8</td>
<td>68.4</td>
<td>18.8</td>
<td>12.5</td>
<td>65.6</td>
<td>3.1</td>
<td>12.5</td>
</tr>
<tr>
<td></td>
<td>Q3</td>
<td>22.2</td>
<td>79.2</td>
<td>24.4</td>
<td>24.4</td>
<td>44.4</td>
<td>6.7</td>
<td>17.7</td>
</tr>
<tr>
<td></td>
<td>Q4</td>
<td>5.71</td>
<td>22.8</td>
<td>37.1</td>
<td>11.4</td>
<td>45.7</td>
<td>5.71</td>
<td>8.5</td>
</tr>
<tr>
<td>2017</td>
<td>Q1</td>
<td>6.5</td>
<td>38.6</td>
<td>24.4</td>
<td>9</td>
<td>50</td>
<td>7.95</td>
<td>12.5</td>
</tr>
<tr>
<td></td>
<td>Q2</td>
<td>15</td>
<td>32.9</td>
<td>27.5</td>
<td>12.9</td>
<td>45.4</td>
<td>3.78</td>
<td>11</td>
</tr>
</tbody>
</table>
The Rainbow Clinic Study

Aims

To explore pregnancy, labour, postnatal experiences and outcomes of women attending the Rainbow Clinic and to assess the wider impact of the service.

Objectives

- Gain insight into women’s experiences of attending the Rainbow Clinic, explore views on the current provision of care and desired aspects of care that enhance patient experience.
- Understand which factors facilitate and prevent effective care.
- Assess the psychosocial well-being of women attending the clinic.
- Use the study findings to develop a user driven model of care, which will inform the development of services in the UK / globally.
Study Criteria

- **Inclusion Criteria:**
  - Women who have had prior stillbirth, neonatal death or late termination of pregnancy
  - Women who are currently pregnant
  - Partners of women who attended the Rainbow clinic

- **Exclusion Criteria**
  - Less than 16 years of age
  - Anyone who lacks capacity to consent
  - Women who have been diagnosed with pregnancy complications and have received treatment for an acute mental health issue in this pregnancy

Rainbow Clinic Study Design

- Interviews
- 32 weeks
- 6 weeks PN

Validated questionnaires
- EPDS
- GAD-7
- EQ-5D
- CWS

<20 weeks
- 32 weeks
- 6 weeks PN
Changes in anxiety / mood over time

• £6.10 return for every £1 invested
Qualitative feedback

“I can’t put financial value to what Rainbow Clinic provides. It is an emotional value”

“My best night’s sleep is on a clinic night”

“Because of Rainbow Clinic, I have the courage to try for another baby”

Measuring Hair Cortisol

- Measure of long-term stress

Control data from Smy et al.
BMC Pregnancy and Childbirth (2016) 16:176
Rainbow Clinic Study - Summary

• Application of various scales to pregnancy after loss demonstrates changes in maternal mental state over time, usually with least symptoms in postpartum period
• Uncertainty over which scales / assessment tools are best to use in this context
• Findings suggest that a dedicated service contributes to a reduction in anxiety and improved experience

Patient Experience Questionnaire

Quarterly Change in Patient Experience Score

Quarterly Change in Standard Deviation of PE score
PEQ Responses to Specific Questions

Qualitative Data - Experience

“I would recommend the Rainbow Clinic without any hesitation. This pregnancy has been tough but it would have been so much more difficult without the support and expertise of the Rainbow Clinic.”

“I would recommend the Rainbow Clinic to another family. The midwife and doc have been lovely and help me after the loss of our little boy.”

“Feels like there should be one in every hospital.”
Conclusions

• Prior stillbirth is a risk factor for a second stillbirth and other adverse outcomes
• Rainbow Clinic Model addresses parents’ needs in a feasible and economically viable way
• Further studies are needed
  – Interpret information from PM + placental exam
  – Inform clinical practice / change management
  – Specific conditions
Rainbow Clinic Website

http://www.mahsc.ac.uk/projects/rainbowclinic/

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