

Objectives

Group B Strep (GBS) is recognised as the UK's most common cause of life-threatening infection in newborn babies (1), and the main cause of meningitis in babies <90 days (2).

Up to a third of GBS infections in babies are late-onset (3), occurring after the baby's first 6 days, usually as meningitis with sepsis. Late-onset group B Strep infection (LOGBS) is uncommon after a baby reaches one month old and very rare after age three months.

Research into LOGBS has rarely focused on the family experience at the time of the baby's illness and subsequently. We use survey data to explore the health, social and financial issues faced by affected families, with a focus on meningitis and sepsis.

Methods

An online survey (n=501) of parents and carers of babies affected by LOGBS was commissioned by charity Group B Strep Support. 94% of respondents were the mothers of the babies and 2% the fathers. We undertook quantitative analysis of responses and a thematic analysis of a significant number of free-text responses.

Respondents were asked to give information about all babies with LOGBS. We asked questions about their awareness of GBS, the clinical course of the baby's LOGBS and about their baby's hospital stay. Finally, we asked about the longer-term health, social and financial consequences of their baby's illness.

Our results rely on parent/carer recall of events and were not crosschecked against medical records.

Results

55% of babies made a full recovery from LOGBS, 32% recovered with long-term sequelae and 13% died. The most common clinical presentations of confirmed LOGBS were sepsis (47%), meningitis (39%) and pneumonia (6%).

Fewer than a third (31%) had heard about GBS before their baby's LOGBS, with almost half (46%) hearing about it during the pregnancy, most commonly (42%) following a urine or swab test.

11% of the babies who developed LOGBS had already had a suspected or confirmed early-onset GBS infection (EOGBS). Almost half (44%) of babies developed LOGBS on days 7 to 14, with three-quarters (75%) by day 31. The most common signs were the baby not feeding as usual (15%), the baby being irritable, unsettled or fretful (13%) and the baby having a high-pitched cry, whimpering cry or moaning.

For the babies not already in hospital, most parents first phoned for help (54%), most commonly their GP or an out of hours GP or NHS Direct/111, and 21% took their baby to A&E and 15% to the GP.

LOGBS was suspected or confirmed within the first 12 hours of being seen by a medical or nursing professional for 45% of babies and 85% within the first 24 hours, although 11 families only received confirmation after their baby had died.

Most LOGBS was confirmed (75%) rather than suspected, and typically diagnosed by lumbar puncture (53%) and/or blood tests (35%).

Hospital stays were significant, with more than half of babies (59%) requiring a stay of 3 weeks or longer (mean 15 days). 49% of these babies were admitted to intensive care for at least some of their inpatient treatment. Intravenous antibiotics were typically given for 7, 10, 14 or 21 days (average 12 days)

72% of parents reported practical difficulties associated with the hospital stay, most commonly being for other children at home (21%), caring for themselves (16%), obtaining food and drink for themselves (16%), and finding parking (11%). Also mentioned were difficulties with paying for parking (13%) and taking time off work (12%).

Most babies recovered from their LOGBS (87%), but 13% of babies passed away. Of the babies who recovered, 64% made a full recovery, with 18% recovering with minor long-term health consequences and another 18% recovering with substantial long-term health consequences.

Most parents rated the explanations given to them about the tests being done on their baby and the treatments given well (65% rated good or very good for the tests, and 77% for the treatments). However, ratings for the explanations of their baby's diagnosis fell to 42%; and for the potential long-term effects on their baby to 35%. 17% of parents reported receiving no explanation about the potential long-term effects.

The impact of LOGBS continued long after the initial illness. Family dynamics were changed, with 29% of parents with other children reporting that siblings experienced difficulty as a result of the baby's LOGBS infection.

54% of parents needed to take time away from work to take their baby to medical appointments as a result of their baby's LOGBS, plus 14% taking bereavement leave.

39% of parents reported financial problems associated with their child's LOGBS; with a third (33%) of these being substantial.

70% of parents reported issues with their own or their family's mental health, 67% reporting reduced enjoyment of subsequent pregnancies as a result of their baby's LOGBS.

Comments from families:

"Both pregnancies that followed, I had planned c sections, which at the time looking after Freya, the recovery of the sections was difficult, the enjoyment of pregnancy and the weeks following the birth of my other children was an extremely difficult and worrying time."

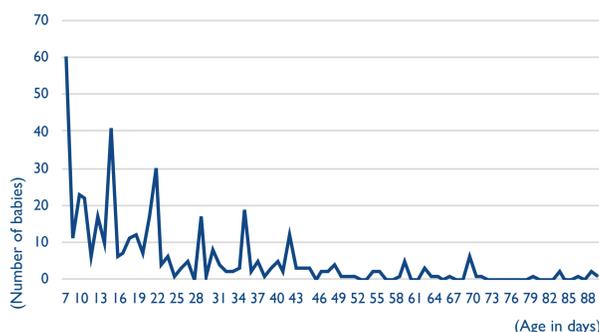
"I would be scared to be pregnant again"

"I had to leave employment, my career"

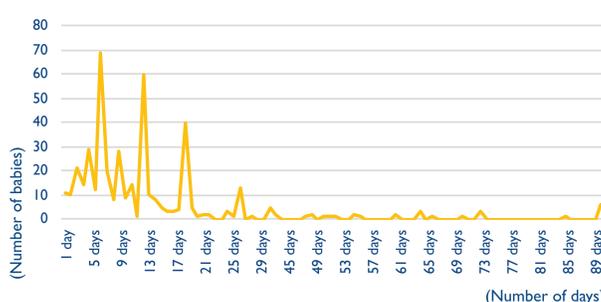
"I was unable to become pregnant after her and now I am too old to become pregnant. It was both a relief and a great sadness. Relieved that I wouldn't have to potentially go through this horrible experience again and sad because we had wanted more children."

"It has made me a very anxious parent. I worried constantly throughout my subsequent pregnancies and worry constantly every day about what could happen."

Age at which babies become unwell

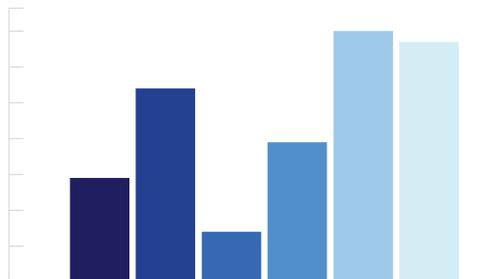


Length of time in hospital



Impacts on the family as a result of a baby's LOGBS

- 70% of parents reported issues with their own or their family's mental health
- 67% reported reduced enjoyment of subsequent pregnancies
- 54% of parents needed to take time away from work to take their baby to medical appointments
- 39% of parents reported financial problems associated with their child's LOGBS
- 29% of parents with other children reported siblings experienced difficulty
- 13% of parents took bereavement leave



Conclusions

These data give a unique insight into what families may be experiencing during and after LOGBS infection, including in subsequent pregnancies. They allow health professionals to reflect on the care, support and information these families may need, and suggest that long term issues remain for many families, impacting mental health and family dynamics, even where the baby has made a full recovery from LOGBS.

At present, there is no prevention for LOGBS – these findings underline the urgent need for a GBS vaccine that will prevent not only the more common EOGBS, but also LOGBS infections.

Bibliography

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2. Government Analytical Volunteer Programme (AVP) <http://gss.civilservice.gov.uk/careers/analytical-volunteerprogramme-avp/>

