Group B Strep: its impact on families and how best to support them

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WORKING TO **STOP** GBS INFECTION IN BABIES.

Group B Streptococcus (GBS) is a normal bacterium carried by adults commonly in the gut or in the vagina, usually with no symptoms or side effects. It is also the most common cause of life-threatening infection in newborn babies in the UK, manifesting most commonly as sepsis or pneumonia and less commonly as meningitis.[1-3] If left untreated GBS can kill a newborn baby within hours.

In the UK, around 800 babies a year aged 0-90 days develop GBS infection and in the majority of babies this occurs as early onset infection in the first 0-6 days of life. Approximately 70 babies die, while 50 recover with life-changing disabilities.[4] That means on average two babies a day develop the infection. Each week a baby dies from GBS infection and another is left with a life-changing disability.

As a charity, Group B Strep Support works to stop GBS infection in newborn babies. Most of these infections can be prevented by providing antibiotic prophylaxis, usually with benzyl-penicillin during labour, to women identified as carrying GBS by testing during the pregnancy.[5]

The UK National Screening Committee does not recommend universal antenatal GBS screening in pregnancy.[6] Other high-income countries, including the USA, Canada, Germany, France and Spain, provide routine antenatal GBS screening in pregnancy.[7] Each test would cost the NHS £12[8] and costs approximately £35 privately. The rate of early-onset GBS infection (EOGBS; 0-6 days) in newborn babies in the UK is two and half times that of the USA.[9] The rate in the USA dropped dramatically following the introduction of routine antenatal GBS testing.[10]

Once a baby develops symptoms and signs of GBS infection, it is too late for prevention. So what can be done to support families who have a baby sick with GBS infection?

The impact on the family

The clinical course of EOGBS and its sequelae are well researched. Most babies become unwell in the first 12 hours of life, and most commonly present with signs of sepsis or pneumonia. Most make a full recovery but approximately 7.4%[4] are left with life-changing disability and about 5.2% die.

The impact on the family both during the hospital stay and afterwards has been less well understood and needs to be considered when thinking about care for the baby and family.

In July 2017, Group B Strep Support undertook an online snapshot survey of parents and carers of babies affected by EOGBS.[11] The survey explored the health, social and other issues faced by affected families, both during their baby's infection and afterwards. Anecdotal evidence had suggested that the impact of EOGBS was longer than just the baby's recovery period, but there was little published data.

There were 996 responses to the Group B Strep Support survey. Parents provided information about their awareness of GBS during pregnancy, whether intravenous antibiotics were given in labour, the clinical course of their baby's infection, their baby's hospital stay and the longer-term consequences of their baby's illness.

In terms of outcomes, the data collected differed from some of the latest British Paediatric Surveillance Unit survey data.[4] The survey found much higher long-term disability rates, and slightly higher mortality rates. Sixty-eight per cent of babies made a full recovery, with nearly a quarter (24%) recovering with long-term health consequences – 60% of these minor, 40% substantial. Eight per cent of babies died (**FIGURE 1**).

The length of hospital stays reported was significant. Three quarters of babies (76%) stayed in hospital for one week or longer, with nearly half staying two weeks or more. The overwhelming majority of babies stayed in hospital for at least five days (92%) and a fifth (20%) were in hospital for more than three weeks.

Nearly nine out of 10 families (89%) reported practical or financial difficulties during their hospital stay – such as caring for other children at

FIGURE 1 The Group B Strep Support survey data: outcomes from early-onset GBS (EOGBS) infection.

home, or finding and paying for parking (**FIGURE 2**). Challenges were varied, but broadly split into four categories: practical, financial, emotional and health difficulties. These challenges were often intertwined. For example, practical difficulties such as caring for other children would lead into emotional difficulties, such as siblings with attachment issues.

One mother summed up the experience of many, saying: "Our main concern was our baby, we were just on autopilot – doing what we had to do to be with him."

And for most families, the impact continued long after the illness. Almost three quarters (72%) of families reported an impact on mental health, with over three quarters (76%) saying their planning or enjoyment of a subsequent pregnancy was affected (**FIGURE 3**). Parents agonised over when, or even if, to have another child. Many significantly delayed having another child, and several families took the decision to have no more children, feeling unable to face another baby's infection.

Almost a third (30%) of families with other children reported the siblings having difficulties because of the baby's EOGBS, and nearly a quarter (24%) of families said they had financial difficulties linked to their baby's infection – such as having to buy specialist equipment, or not being able to return to work as they were now a full-time carer for their baby.

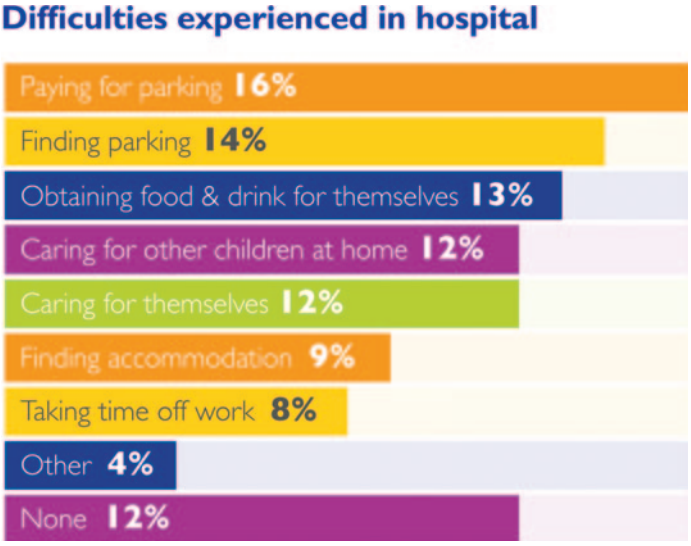

FIGURE 2 Nearly nine out of 10 families reported practical or financial difficulties during their hospital stay.

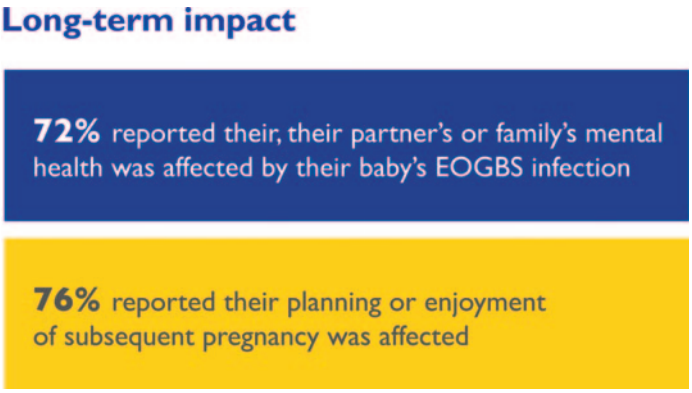

FIGURE 3 Affected families reported that the impact of GBS continued long after the illness.

How Group B Strep Support can help

As the national charity working to prevent GBS infection in babies, Group B Strep Support strives to work in partnership with health and care professionals to support families affected by GBS.

The charity runs a helpline that provides confidential one-to-one support and information, Monday to Friday 9am-3pm (telephone: 01444 416176, email: info@gbss.org.uk). Often families find it beneficial to contact the helpline to discuss their concerns. Group B Strep Support provides up-to-date information on GBS and signposts families to resources providing more information or support. It can also connect them with other families to share their experiences of GBS.

Group B Strep Support is supported by an expert medical advisory panel and produces high-quality patient information materials. There are two leaflets written specifically for families who have had a baby affected by GBS infection. Firstly *Understanding your Baby's Group B Strep Infection* which explains what GBS infection is, what treatments a baby might be given, and how GBS might affect a baby.[12] The charity also provides a more detailed leaflet, *After Your Baby's Group B Strep Infection*, for families wanting further information and support.[13] It covers a range of topics, including how families can get more details about what happened to their baby, what to do if a baby needs continuing care, suggestions on how to create memories of their baby if he or she has died, and information on what should happen in any future pregnancy. Both leaflets are free-of-charge to families and the NHS – please contact Group B Strep Support to order copies.

How you can help Group B Strep Support

July is GBS awareness month and, while it is incredibly important that families get the right support when their baby is sick, ideally prevention is better than cure. To get involved, visit www.gbss.org.uk/awarenessmonth.

Many families first hear about GBS when their baby is sick in the neonatal intensive care unit. Group B Strep Support wants families and pregnant women to find out about GBS when they can prevent this happening in the first place – during pregnancy.

The charity has worked in partnership with the Royal College of Obstetricians and Gynaecologists (RCOG) to produce a patient information leaflet that explains to parents when a baby is at increased risk of EOGBS infection, and how to reduce that risk.[14] The RCOG's Green-Top clinical guideline recommends this leaflet should be provided to all pregnant women.[15] Group B Strep Support is fundraising to provide free hard copies of this leaflet to all NHS maternity units in the UK. Please check that your hospital is using these leaflets and, if not, ask that they contact Group B Strep Support for supplies.

Acknowledgement

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References

1. **Muller-Pebody B, Johnson AP, Heath PT, et al.** Empirical treatment of neonatal sepsis: are the current guidelines adequate? Arch Dis Childhood Fetal Neonatal Ed 2011 doi: 10.1136/adc.2009.178483.
2. **Okike IO, Ribeiro S, Ramsay ME, et al.** Trends in bacterial, mycobacterial, and fungal meningitis in England and Wales 2004-11: an observational study.

Lancet Infect Dis 2014;14:301-07.
3. **Depani SJ, Ladhani S, Heath PT, et al.** The contribution of infections to neonatal deaths in England and Wales. Pediatr Infect Dis J 2011;30:345-47.
4. **BPSU.** British Paediatric Surveillance Unit: Annual Report 2015-2016. Online at: www.rcpch.ac.uk/bpsu.
5. **Lin FY, Brenner RA, Johnson YR, et al.** The effectiveness of risk-based intrapartum chemoprophylaxis for the prevention of early-onset neonatal group B streptococcal disease. Am J Obstet Gynecol 2001;184:1204-10.
6. **UK National Screening Committee.** The UK NSC recommendation on Group B Streptococcus screening in pregnancy. 2017. Online at: https://legacyscreening.phe.org.uk/groupbstreptococcus
7. **Le Doare K, O'Driscoll M, Turner K, et al.** Intrapartum antibiotic chemoprophylaxis policies for the prevention of group B Streptococcal disease worldwide: systematic review. Clin Infect Dis 2017;65:S143-51.
8. **Colbourn T, Asseburg C, Bojke L, et al.** Prenatal screening and treatment strategies to prevent group B streptococcal and other bacterial infections in early infancy: cost-effectiveness and expected value of information analyses. Health Technol Assess 2007;11:1-226.
9. **Centers for Disease Control and Prevention.** Active bacterial core surveillance (abcs) report emerging infections program network Group B Streptococcus, 2016. 2018. Online at: www.cdc.gov/abcs/reports-findings/survreports/gbs16.pdf.
10. **Koenig JM, Keenan WJ.** Group B Streptococcus and early-onset sepsis in the era of maternal prophylaxis. Pediatr Clin North Am 2009;56:1-22.
11. **Stanley A, Plumb O, Betts C, Plumb J.** Impacts of early-onset group B Strep infection – perspective from families. 2018. Online at: https://gbss.org.uk/wp-content/uploads/2018/05/2018-ISSAD-EOGBS-Survey-Presentation-FINAL2_001.jpg
12. **Group B Strep Support.** Understanding your baby's group B Strep infection 2015. Online at: https://gbss.org.uk/product/free-leaflets-understanding-your-babys-group-b-strep-infection/
13. **Group B Strep Support.** After your baby's group B Strep infection. 2018. Online at: https://gbss.org.uk/wp-content/uploads/2018/05/2018_03-After-your-babys-group-B-Strep-infection.pdf.
14. **Royal College of Obstetricians and Gynaecologists and Group B Strep Support.** Group B Streptococcus (GBS) in pregnancy and newborn babies. 2017. Online at: https://gbss.org.uk/wp-content/uploads/2018/01/2017-Joint-RCOG-GBSS-PIL_final.pdf.
15. **Hughes RG, Brocklehurst P, Steer PJ, et al on behalf of the RCOG.** Prevention of early-onset neonatal Group B Streptococcal disease: Green-top Guideline No 36. BJOG 2017;124:e280-305.

NEWS

Do mothers sound good?

Although developmental care interventions are meant to facilitate mother-infant bonding, physical contact in the NICU is not always possible. Maternal voice exposure has been proposed as a way to foster maternal closeness and support postnatal bonding in the NICU.

A systematic review published in *Neuroscience and Biobehavioral Reviews* on maternal voice and development of preterm infants revealed wide differences in maternal voice exposure methods and inconsistent physiological outcomes (eg heart rate variability, oxygen saturation, number of critical alarm events). However, a robust pattern of findings emerged for feeding behaviours, as well as cognitive and neurobehavioural development. Maternal voice appears to be a non-harmful intervention, which is consistent with developmental care and can facilitate intimacy between mothers and infants in the NICU.

Reference

Provenzi L, et al. Do mothers sound good? A systematic review of the effects of maternal voice exposure on preterm infants' development. Neurosci Biobehavioral Rev 2018;88:42-50.

Survival of preterm infants continues to improve

A study published in *Archives of Disease in Childhood – Fetal and Neonatal Edition* analysed survival trends and regional variation for very preterm infants admitted to neonatal care in England 2008-2014. The authors modelled survival probability in over 50,000 eligible infants with birth weight, gestational age, sex, antenatal steroid exposure and multiple birth.

The findings showed that survival of preterm infants admitted to neonatal care has continued to improve, particularly for infants at lower gestational ages. However, there is regional variation and improvements have not been consistent across the country; there was an increase in survival over 2008-2014 that largely occurred in London and the south of England.

Reference

Santhakumaran S, et al. Survival of very preterm infants admitted to neonatal care: time trends and regional variation. Arch Dis Childhood Fetal Neonatal Ed 2018;103:F208-15.

Optimising oxygen saturation targets in extremely preterm infants

An article published in *JAMA* by the Neonatal Oxygenation Prospective Meta-analysis (NeOProM) Collaboration compared the effects of different target ranges for oxygen saturation, as measured by pulse oximetry (SpO_2), on death or major morbidity among extremely preterm infants.

The meta-analysis of individual participant data found no significant difference between a lower oxygen saturation (85-89%) compared with a higher saturation (91-95%) on the primary composite outcome of death or major disability at a corrected age of 18 to 24 months. However, the lower SpO_2 target range was associated with a higher risk of death and necrotising enterocolitis, but a lower risk of treatment for retinopathy of prematurity and no increased risk of blindness.

Reference

Askie LM, et al. Association between oxygen saturation targeting and death or disability in extremely preterm infants in the Neonatal Oxygenation Prospective Meta-analysis Collaboration. JAMA 2018;319:2190-201.