Removing barriers to effective care of infants with necrotising enterocolitis

Joanne Ferguson
Parent Representative
Special Interest Group in
Necrotising Enterocolitis
(SIGNEC)
contact@signec.org

My son Guy died of a disease that is feared by neonatal professionals but which I, like most other parents, had never heard of before he contracted it: necrotising enterocolitis (NEC). After his dreadful death, I struggled to understand why there was so little information on the disease and at one of the first meetings of the Neonatal Critical Care Clinical Reference Group I suggested that a national data collection system could be put forward for an innovation fund that was briefly proffered to specialised services. The idea was dismissed but I was given the name of the doctor who had organised the first conference of the Special Interest Group in Necrotising Enterocolitis (SIGNEC)[1] and last year Dr Minesh Khashu and I were able to produce a website (www.signec.org). It is intended to help professionals and families, and one of the contributors to its blog section is Professor David Hackam, Chief of Pediatric Surgery and Surgeon-in-Chief at Johns Hopkins Children's Center in Baltimore, USA, who is a gifted communicator as well as a NEC expert.

Knowledge vacuums

"It is a sad and frightening truth," he writes, "that in many cases, the very first time that families will have heard of NEC – this awful menace putting their child's health in mortal danger – is when their precious baby has begun to fight it. It is as if the first time you had ever heard about a heart attack was when you were experiencing crushing chest pain. How can this be – that our families experience this devastating disease from such a knowledge vacuum and how, as a profession, can we remove this barrier to effective care?"[2]

There is considerably more information and support for parents of premature babies than there used to be, yet an international survey by the US-based NEC Society found that information about NEC was predominantly shared verbally and that the majority of respondents were not satisfied with the information they were given before or after diagnosis.[3] Information and education are essential aspects of family-centred care yet few hospitals in the UK provide written information on this lethal disease, so I hope the SIGNEC website will help professionals and parents to discuss it. I will never forget my ineptitude when a surgeon and neonatologist waited for me to ask questions and decide what to do, which is why Dr Khashu and I are trying to find funding for an animated film to help parents make informed choices. For people familiar with YouTube, text is not enough.

The young film producers I approached knew nothing about premature babies, never mind NEC, and there is still a gaping knowledge vacuum surrounding prematurity. Parent advocates can work together virtually on World Prematurity Day (17 November) and on the first international NEC Awareness Day that was held on 17 May, but traditional forms of health education still matter. Posters and leaflets in clinics where mothers receive antenatal checks could introduce parents to categories of care and complications of prematurity because the first time they realise a neonatal unit does not look after the sickest babies, or that not every neonatal intensive care unit has surgeons close by, should not be when their baby has severe NEC.

Mention the menace

We also need to do more to bring premature babies into breastfeeding campaigns and conferences. Their distinct immune system places them at high risk of developing life-threatening infections,[4] yet outside of neonatal settings, they rarely feature in meetings and materials promoting the medicinal powers of breast milk. I have lobbied for a conference and public statement dedicated to their nutritional needs, and am delighted that, as part of its campaign to improve breastfeeding rates, the Public Health Agency in Northern Ireland has a web page[5] devoted to premature babies that raises the spectre of NEC. I would also like to see campaigns that educate us about our gut microbiota acknowledge that bacterial colonisation is a risk to immature intestinal tracts. If we mention the menace of NEC

Barrier to care	Ways to overcome
Incomplete understanding of the disease	Bring NEC into wider health campaigns
Lack of public awareness	Use multiple modes to communicate information
Not enough investment in research	Greater emphasis on the need for data
Lack of accurate data	More investment in research and quality improvement

TABLE 1 Barriers to care for infants with NEC and ways to overcome them.

in wider health campaigns, we can reduce the lack of awareness and promote the need for more research into the disease (**TABLE 1**).

Put costs in perspective

The susceptibility of the most premature infants to intestinal diseases should be a part of discussions about feeding. However, we cannot preach about the preventive powers of breast milk and not provide pumps for mothers with babies in neonatal and paediatric units. Some have to pay deposits for pumps to use at home or get charities to help, which adds to their stress levels and diminishes all the other efforts made to persuade them to breastfeed. Hospitals have to put the cost of purchasing and replacing pumps in perspective. Would they prefer to do all they can to prevent NEC or pay for babies who later need a liver transplant or are still in hospital a year after they first needed emergency surgery?[6]

Insights from accurate data

The monetary burden NEC places on our health system has not been fully researched but studies in the USA have found that the average total treatment cost per NEC patient was $500,000.[7] We will not significantly reduce the money spent treating babies, or the immeasurable costs to bereaved families and those with children left disabled, if we do not put much more emphasis on research and the capacity to gain insights from accurate data.

We still do not have a system for collecting and publishing national data on NEC, and I wrote to Jeremy Hunt, Secretary of State for Health and Social Care, about this after he announced the government's ambition to halve rates of stillbirths and neonatal deaths by 2025.[8] Rare diseases cause around a third of infant deaths, and the Royal College of Paediatrics and Child Health has highlighted the need to improve infant mortality data.[9] If politicians are to achieve "outcomes at scale",[10] they need to confront the costs of combining data from units that care for sick infants across the UK.

Public Health England recently established the National Congenital Anomaly and Rare Disease Registration Service and it supports a European portal for rare diseases called Orphanet (www.orpha.net). Yet there is nothing on there to show what is being done about the most common life-threatening gastro-intestinal emergency in premature infants, which is a disservice to all the babies NEC affects. In the USA, the National Organisation of Rare Disorders operates a NEC Registry.[11]

The lack of appropriate definitions and data sets for NEC have been considerable barriers to improving understanding and outcomes, yet so has inertia. It is heartening that efforts to change this have been gathering pace and that more people than ever are working and collaborating to overcome this dreaded disease.

References

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The sixth annual SIGNEC conference will take place on 29-30 October 2018 at Chelsea Football Club in London.

For further information visit **www.signec.org**

Joanne Ferguson (second from left) and Minesh Khashu (far right) with some of the speakers at the fifth SIGNEC conference in 2017.