Feature

The after-effects of childhood meningitis

Every year on April 24, members of the Confederation of Meningitis Organisations (CoMO) mark World Meningitis Day. The theme for 2019 is life after meningitis. CoMO has issued a five-page toolkit outlining key messages, as well as several infographics in different languages and a factsheet listing the sequelae of meningitis. But it is the personal stories in the videos and testimonials on the CoMO website that provide the most powerful description of the dreadful long-term consequences of the disease.

"When my sister Ashleigh contracted meningitis, my parents, other sister and I became her carers for life", states Jess from Australia, in one of the testimonials. "We share showering, feeding and sitting duties and each make personal sacrifices for her care. If anything happens to my parents, my sister and I will become Ash's primary carers, an adjustment our partners and children will also have to make." Ashleigh contracted pneumococcal meningitis when she was 6 months old. It was touch and go for a while, but she survived. When she left the hospital, she was blind. Her sight returned, though not before 18 months had passed. But the deafness was permanent, as were the cerebral palsy and epilepsy. A spinal fusion proved necessary to address the severe scoliosis. Ashleigh uses splints to help her walk and sometimes requires a wheelchair. She has never spoken.

Yet, despite their potentially devastating consequences, the sequelae of meningitis have historically been neglected, both in terms of research and in terms of follow-up services in the countries where the bulk of the disease occurs. Bacterial meningitis is associated with some of the most serious after-effects. Aside from the conditions that have affected Ashleigh, bacterial meningitis has been linked to acquired brain injury, learning difficulties, lapses in concentration, mood swings, depression, exhaustion, memory loss, clumsiness and problems with balance, and tinnitus. If the meningitis was accompanied by sepsis, there is a risk of limb loss and organ failure. Viral meningitis is milder, but has been linked to some of the same cognitive after-effects as the bacterial form, particularly among those who contract the disease as newborn babies.

An estimated 20% of survivors of bacterial meningitis are thought to experience at least one after-effect. But this figure is little more than a rough guide. The limited research that has been done in those who contracted meningitis prior to adulthood suggests that the chances of developing life-changing conditions are considerably higher. A 2011 literature review concluded that half of survivors of childhood bacterial meningitis had some kind of long-term sequelae, and over a fifth were left with hearing impairments or neurological deficits. A study of 36 individuals who survived bacterial meningitis in their childhood or adolescence noted that the vast majority reported being dizzy and unsteady on their feet. A large-scale Danish study linked meningitis in childhood to subsequent lower educational achievement.

A study in the UK found that an episode of meningococcal group B disease in childhood was associated with a one in three risk of sequelae; survivors were five times more likely to have speech or communication problems than the general population. At the time, meningitis B was the most prevalent type of bacterial meningitis in the country, infecting some 1700 children every year. But in 2015, the UK became the first nation in the world to introduce the meningococcal B vaccine into its routine childhood immunisation schedule. That ought to drive down the incidence of sequelae. *Haemophilus influenzae* type B, which was once the most common cause of hearing loss in children, has been eliminated from many high-income countries thanks to a vaccine that is thought to have saved 1·2 million lives in 2000–15. However, although important, vaccination on its own will not solve the problem.

Since 2010, 270 million doses of the meningococcal A vaccine have been distributed in the meningitis belt, which stretches from Senegal to Ethiopia. But the region still sees outbreaks of other serotypes, including 18 000 reported cases of meningitis C in Niger and Nigeria in 2017. Besides, although the meningitis belt is prone to epidemic meningitis, most of Africa's cases occur elsewhere. There are no vaccines against viral meningitis, tuberculous meningitis, and cryptococcal meningitis—and very little is known about the after-effects of the last two. Nor is there a vaccine for

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For **CoMO** see http://www.comomeningitis.org/

For **CoMO's toolkit for World Meningitis Day 2019** see http://www.comomeningitis.org/world-meningitis-day/wmd-2019/world-meningitis-day-toolkit-2019/

For the **literature review on the long-term sequelae of childhood bacterial meningitis** see *Pediatr Infect Dis J* 2011; **30:** 3–6

For the **study on childhood meningitis and postural control** see *PLoS One* 2014; **9:** e112016

For the **study on educational achievement after childhood meningitis** see *JAMA* 2013; **309:** 1714–21

For the **outcomes of meningococcal group B disease in children** see *Lancet Neurol* 2012; **11:** 774–83

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For **WHO's meningitis baseline situation analysis** see https://www.who.int/immunization/research/BSA_20feb2019.pdf

For the **paper on the aftercare for children surviving meningitis and septicaemia** see *BMC Public Health* 2013; **13:** 954

group B streptococcus, a pathogen that kills around one in ten infected babies. "Group B streptococcus meningitis can have major sequelae; it is extremely important that it is recognised early and treated", said Lee Hudson (University College London, London, UK), co-investigator of the UK study on meningococcal group B disease.

WHO reckons that in 2016 around 280 000 people died from meningitis; the Global Burden of Disease estimates put the figure at nearer 320 000. Both estimates came with wide confidence intervals. The nature and prevalence of the sequelae of meningitis, whether in survivors of childhood or adult disease, is even less certain. Research into the sequelae of meningitis is tricky and time-consuming, and has not tended to be well funded. "There is a real paucity of data", explains Robert Heyderman (University College London, London, UK). "Even in rich countries, the long-term consequences of meningitis are really poorly defined; when it comes to countries outside Europe and North America, we know very little."

For example, bacterial meningitis is associated with behavioural change, including aggression, but the extent of the problem is unclear. "We are discovering more and more about the neurological impact of things like head injuries and encephalopathies; based on that, the long-term behavioural consequences of meningitis could very well be severe, we just do not know", said Heyderman. After all, parents could be forgiven for failing to realise that their 6-year-old's temper tantrum is linked to the meningitis they experienced a few years earlier.

Cognitive impairment also tends to be under-recognised. And like behavioural disorders, it tends to manifest much later. A child may only start showing signs several years after the episode of meningitis. "You have to be aware that there is a good chance that a child who has recovered from meningitis is going to be a bit different for a while", points out Samantha Nye, chief executive of CoMO.

UK guidelines stipulate that children who are diagnosed with bacterial meningitis or meningococcal septicaemia should have their hearing tested, with a follow-up review with a paediatrician 4–6 weeks after being discharged from hospital. "For hearing loss in particular, you do have act quickly—a cochlear implant needs to happen before the damage becomes too advanced", said Nye. But in many low-income countries, follow-up services for meningitis are more or less non-existent. "Public awareness on the sequelae really varies both between and within nations", adds Nye. "Some places will signpost to available services and make clear the things parents need to look out for; in other places, there are real gaps."

Nonetheless, the outlook for survivors of meningitis looks set to improve. WHO is working on a global roadmap to defeat meningitis by 2030. The initiative emerged after two high-level meetings of government officials and health experts in 2017. It is still in its infancy—what exactly will constitute "defeat" has yet to be defined. But a meeting of WHO's technical taskforce in 2018 stipulated three strategic goals: ending meningitis epidemics, reducing the incidence and mortality from vaccine-preventable meningitis by 80%, and ensuring that survivors with sequelae are provided with high-quality care.

"For the first time, people are talking about the long-term health consequences as an important component of defeating meningitis", notes Heyderman. In a report analysing the baseline situation in preparation for the roadmap, WHO specifically mentioned support and after-care for survivors and their families. It stressed the importance of ensuring "that survivor care is seen as an intrinsic part of any meningitis response—a distinct strand but fully integrated in these responses". The authors pointed out that there is no standard model encompassing all the aspects of post-meningitis care, and that survivors will require tailored rehabilitation programmes. They emphasised the need for "a paradigm shift…in the way we think about meningitis, to recognize the functional and psychosocial sequelae of meningitis whilst at the same time taking action to integrate responses within existing initiatives in the disability and support field".

Preparing clinicians, patients, and parents for what might come after the acute phase of meningitis is an indispensable part of any response to the disease. "Unless they are flagged up, people may not know the correct actions that need to be put in place and may not be able to reverse or help to correct some of the sequelae", Heyderman told *The Lancet Child & Adolescent Health*. That could mean the difference between a youngster with weakened limbs being assigned to a physiotherapist and having to cope on their own. "It is about informing families that there is the possibility of sequelae and then making sure that those children who are identified as having problems later in life are able to access support", adds Hudson.

Parents need to be linked to the available support services. These might include patient and civil society organisations, speech and language therapists, physiotherapists, and paediatricians. "It is amazing how much can go into recovering from meningitis for even one individual", said Nye. The authors of a paper on children who have survived meningitis and septicaemia suggested that parents are offered a comprehensive debriefing prior to their child's discharge from hospital. Such a strategy would raise awareness of the sequelae, as well as help parents accommodate the uncertainty that comes with meningitis survivorship. After all, as Jess, sister of Ashleigh, points out in her testimonial: "Meningitis doesn't just affect one person in one moment. It affects many across a lifetime."

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