Counting long covid in children

October 16, 2020

With the recent announcement that the NHS will provide services for patients with long covid, there was a palpable sense of triumph among the community of long haulers. We both have long covid and are active campaigners for this condition. We should have been elated; after all, this was the recognition campaigners had been advocating for since the release of the video "Message in a bottle—Long Covid SOS." Although we are pleased by this commitment from the NHS to recognise long covid, we have ongoing concerns about the lack of paediatric services for children with covid-19.

One of us (Frances Simpson) is a mother of two children who have also been experiencing symptoms for almost seven months, and has met many other parents whose children have had covid-19. Existing research shows that children have generally been found to have less severe covid-19, but there is concern among campaigners that paediatric long covid has received much less attention. Many of the parents in online support groups share this concern, describing their fear at the strange and fluctuating symptoms experienced by their children, their frustration at the lack of medical care, and their struggles to be believed.

When the World Health Organization extended an invitation to the campaign group LongCovidSOS to share experiences of long covid, Frances took the opportunity as a speaker at the meeting to present the narratives of children and parents who have symptoms of long covid. She shared the views from the many long covid support groups on social media, as a means of drawing attention to the possibility that symptoms of long covid may extend to children. The quantification of this was impossible due to the lack of empirical data. However, with this in mind, she conducted an informal poll on closed social media groups including the Body Politic/Slack support group, the LongCovid Support Group, and the Parents of Longhauler children support group on Facebook. There are of course limitations to a survey of this kind due to selection and other types of reporting biases, but in the absence of any existing data, this was a scoping exercise.

Parents reported that their children experienced fatigue, general gastrointestinal issues, sore throats, headaches, and muscle pain, or weakness. Other symptoms included fevers, nausea, mood changes, rashes, dizziness, breathing difficulties, and cognitive blunting. The findings of this very informal patient-led survey demonstrate that there is a need for further epidemiological data collection, in order to quantify and qualify the existence of long covid in children. There is also a need for research into pathophysiology of these symptoms as is being currently investigated in adult cohorts.

When children presented with this new multisystem disorder in the first wave of the epidemic, some primary care and secondary care doctors were unaware of the full spectrum of disease manifestation. Parents from the long covid social media groups have expressed upset that they encountered "medical gaslighting," or a trivialisation of their parental concerns. Parents have voiced fear that they may be branded as "Munchhausens by proxy" parents in their persistence to ask for healthcare support for their children.

There is a need for clinicians, at primary and secondary care levels, to be alert and aware of the multisystem symptoms in children through rapid guidelines or continual professional development. There is also a need for parents to be aware that this may explain ongoing issues that may come and go in the aftermath of a covid-19 infection. Existing data show that severe covid-19 is less likely in children. As the pandemic continues to evolve, we must continue to collect and analyse more data and listen to patient narratives to help inform the management of long covid and any policy implications that arise from these findings.

Frances Simpson *is a lecturer in psychology and counselling at Coventry University (SC.) She is also a sufferer of long covid and a founder member of the campaign group LongCovidSOS.*

Amali Lokugamage *is a consultant in obstetrics and gynaecology at Whittington Health NHS Trust, London, UK, and honorary associate professor and deputy lead of clinical and professional practice at UCL Medical School, London.*

Competing interests*: AUL is on the board of directors of the International MotherBaby Childbirth organisation. She is a company director of a small publishing company called Docamali Ltd. FS none declared.*

Patient and public perspectives

« Ian Hamilton: Drug related deaths are not spread equally in our communities

Amitava Banerjee: Communicating risk in the time of corona »

ALSO ON BMJ BLOGS

John Middleton: Is the NHS prepared for the …
2 years ago · 1 comment
Recent NHS performance data show that the NHS is currently under huge …

Government indecision is still costing lives in …
2 years ago · 1 comment
The government must act now, or be faced with much tougher decisions and …

Richar
life wo
2 years a
"What is
questio
answer