

Children with Long Covid: Co-producing a specialist community public health nursing response

› Abstract

Globally, children have been profoundly affected by the Covid-19 pandemic in many ways. While the majority of children with acute Covid-19 infection experience mild illness and fully recover, many go on to experience Long Covid. Long Covid is clinically identified by experience of persistent (and sometimes different) symptoms for several months after the acute infection (even in children who were asymptomatic). There is currently no agreed consensus on the case definition of Long Covid, but real-world data from American health insurance firms and the UK Office for National Statistics report that children may experience intestinal symptoms, pain, breathlessness, cognitive dysfunction and post-exercise malaise. The current understanding of the natural history, diagnostics and treatments of Long Covid is limited, meaning the medical model in isolation is not helpful. Health visitors and school nurses are ideally placed to case-find children with Long Covid and co-produce child and family-centred care.

Key words

› Long Covid › Children › Long-term conditions › Health visiting
› School nursing › Co-production

The Covid-19 pandemic has brought many challenges to children, families, communities and societies across the world, with governments responding through unprecedented emergency reprioritisation of health services, the creation of socially significant pandemic rules and the roll-out of national mass vaccination programmes. Until recently, children in the UK have been considered

inconsistently throughout the pandemic (Holt and Murray, 2021), largely because they are thought to be less affected by the SARS-CoV-19 virus with milder symptomatology and a better prognosis, when compared with adults in acute infection (Ludvigsson, 2020a; Zimmerman and Curtis, 2020). Although emerging evidence of the impact of the Delta variant (B.1.617.2) in the USA shows greater transmissibility, symptom severity and hospitalisation in children than with earlier forms of the virus.

Children have perhaps suffered more from societal changes than from the virus itself, including the closure of schools, social isolation due a lack of peer support and structure and, for some, the necessary protection from abusive home environments (Baginsky and Manthorpe, 2020; Crawley et al, 2020; Garstang et al, 2020) as well as no access to free school meals (Parnham et al, 2020). In an online survey of 927 UK-based caregivers, Morgül et al (2020) identified a notable increase in boredom, loneliness and frustration among children during lockdown, with family co-existence described as ‘moderately difficult’.

Similarly, Waite et al (2021) found significant increases in emotional symptoms, hyperactivity and inattention, and conduct problems in children from survey data from 2673 UK-based caregivers during the first national lockdown. The social, emotional, educational and physical effects of the pandemic on children are likely to be profound and long lasting.

Beyond the acute phase of Covid-19 infection

Early in the pandemic it was assumed that Covid-19 was a respiratory infection, and that enduring symptoms needed respiratory rehabilitation. We have come to learn over the past year that Covid-19 is a multi-system disease (National Institute for Health Research (NIHR), 2021) affecting at least 10 organs (Roberts et al, 2020) and that not everyone has acute respiratory symptoms. The virus attaches itself to angiotensin-converting enzyme 2 receptor-expressing cells

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all over the body, resulting in a diverse range of symptoms in acute infection (Ni et al, 2021). As 2020 progressed, a post-acute Covid-19 illness began to be seen and was described by people with lived experience as 'Long Covid'. The causal factors are unclear, but may include a continuing infection, damage caused by the acute infection or the body's response to the infection. Long Covid is a term used by those with lived experience, deliberately chosen to avoid the epistemic inferences of medical terms such as post-Covid syndrome or post-acute sequelae of Covid-19 (Callard and Perego, 2021).

More recently, there has been increasing evidence to show that children and young people can also suffer from Long Covid. It is not related to the severity of the initial Covid-19 infection in adults, and one study found that 19% of those who tested positive but were asymptomatic went on to experience Long Covid symptoms (FairHealth, 2021).

Most people who have had a Covid-19 infection go on to full recovery, but a significant number continue to have re-emerging and/or persistent symptoms, sometimes different from those in their acute infection (if symptomatic). There are almost certainly a number of different syndromes and phenotypes that are broadly captured under the term 'Long Covid'. Attempts to produce a clinical case definition have been made by a number of bodies (using different nomenclature), none of which is particularly helpful for diagnosis. For example, the National Institute for Health and Care Excellence (NICE) defines Long Covid as (2020: 8):

'Signs and symptoms that continue or develop after acute Covid-19 (up to 4 weeks). It includes both ongoing symptomatic Covid-19 (from 4 to 12 weeks) and post-Covid-19 syndrome (12 weeks or more).'

It notes that post-Covid-19 syndrome is (2020: 7–8):

'not explained by an alternative diagnosis ... [and] usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-Covid-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.'

'Long Covid' is an umbrella term that includes a large number of people who experience post-viral fatigue, which resolves spontaneously within 12 weeks and ranges from mild discomfort

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to severe disability. Up to a third of people may have symptoms for 12 months or more (Whitaker et al, 2021). Two Long Covid clinics have identified difference between hospitalised and non-hospitalised patients (Heightman et al, 2021; O'Sullivan et al, 2021). Long Covid includes people who have been critically ill (including children with paediatric multi-system inflammatory syndrome) and are experiencing post-intensive care syndrome, some with clear organ damage from the initial viral attack. However, many people outside these groups remain ill more than 12 weeks later, with small studies showing organ damage, raised D-dimers (indicating blood clots), dysautonomia and autoantibodies. In addition, the US medical insurance company, UnitedHealth Group, reports that 14% of people with confirmed or suspected Covid-19 infection receive a new diagnosis requiring medical attention in the subsequent 6 months, with the most common new diagnoses being hypertension and diabetes (Daugherty et al, 2021).

As yet, there is no reliable indicator of risk and no simple test to triage people for more detailed diagnostics. Therefore, health visitors and school nurses must be alert to 'red flags' for physical conditions that may deteriorate in anyone self-reporting Long Covid. The lack of consensus on case definitions reflects the emerging evidence base and means that health visitors and school nurses must use their professional judgment. This uncertainty has led sceptics in healthcare professions (particularly those who have not read the research) to dismiss people, especially children, who report Long Covid. It is perhaps unsurprising that a case definition in children has not been agreed.

Emerging epidemiology in children

One of the largest data sets comes from the Office for National Statistics (ONS), using its Coronavirus Infection Survey, which is completed monthly by 140 000 randomly sampled households from all parts of the UK, involving all sampled household members aged 2 years or over. In August 2021, 380 000 people (including 7 000 aged 16 and under) reported symptoms lasting over 12 months in the UK (ONS, 2021). While Long

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Covid in children has a prevalence rate around half that of adults, the ONS estimates that 34 000 children aged 16 and under have had Long Covid symptoms for 12 weeks or more, and 7000 for over a year. Given the emergent evidence that children may have a different set of symptoms, this may be an underestimate.

Initial assumptions that Long Covid did not occur in children were challenged by parents and in case reports by hospital paediatricians (e.g. Ludvigsson, 2020b). Traditional literature searching is constrained by the lack of MeSH heading(s) and the different terms used internationally. Long Covid is an ill defined term, and every study uses different case definitions, different inclusion and exclusion criteria and measures symptoms at different time points.

Surveys of the prevalence in children began to be published at the beginning of 2021, and characteristically are cross sectional and do not capture the well described relapsing and remitting nature of the condition, nor the fact that people with asymptomatic infections can develop Long Covid weeks later. All studies to date are observational studies, some self-selected (e.g. Molteni et al, 2021) and all have methodological limitations.

Long Covid appears to have an inverted U-shaped age distribution, with those aged 20–69 most at risk. While there is lower prevalence in children, and young and older people, Long Covid is still a debilitating condition for these groups. Unlike acute illness with Covid-19 infection, which is more frequent in men, 59% of those with Long Covid at 12 weeks and 57% of those with Long Covid for at least a year are women. This may be an underestimate, as the symptoms that women experience uniquely, including disrupted menstrual cycles and in children, early menarche (Centers for Disease Control and Prevention, 2021), are not included in the ONS symptoms list.

From an online survey with an international cohort of 56 countries, Davis et al (2021) estimated up to 203 different symptoms of Long Covid. Public Health England has identified three

different clusters of symptoms, including sensory (ageusia, anosmia, loss of appetite and blurred vision); neurological (forgetfulness, short-term memory loss and confusion/brain fog); and cardiorespiratory (chest tightness/pain, unusual fatigue, breathlessness after minimal exertion/at rest, palpitations) (Amin-Chowdhury et al 2021).

Other real-world data includes analysis of health insurance claims in the USA. FairHealth (2021) reviewed claims of nearly 2 million people (including children) and found that Long Covid symptoms vary by age, with intestinal problems, pain and breathlessness being the top three for children. Cognitive dysfunction ('brain fog') and post-exercise malaise are also common in children (FairHealth, 2021), and need individualised support rather than a generic rehabilitation plan. As yet, there is little published evidence on biomarkers of Long Covid in children, but this is likely to be an absence of evidence rather than evidence of absence.

The nursing profession

Since the beginning of the pandemic, there have been media-facilitated public displays of conflict from previously trusted sources, with differing interpretations of the same emerging evidence, including the use of face masks, vaccines and implementation of lockdowns. There have been disagreements between ardent advocates of evidence-based medicine, policy advisers, clinicians and politicians involved in government pandemic decision-making (Watson and McCrae, 2020). This public discourse has created confusion about the scale of the issues, and individual nurses have drawn on personal lived experience and professional encounters with children and families. These have often been counter to the media narratives, particularly for children with Covid-19 infection and those with persistent Covid-19 symptomology (Long Covid).

The role of nursing has long been as patient advocate, educator and adviser, but this has barely been visible in relation to Covid-19 (Anders, 2021), and parents have sought support from each other through support groups. Most Long Covid clinics have been established without any nursing, health visiting or school nursing input. Maxwell and Radford (2021) observe that this oversight reflects the lack of theoretical underpinning of the nursing contribution, especially with the leadership, research and delivery of longer-term health service responses. Rather than a recovery from acute infection, Long Covid is better seen as a mid-to long-term condition.

Nurses have demonstrated a pivotal role in supporting people with other long-term conditions, in particular, in managing uncertainty, co-producing personal coping strategies, health promotion, ‘red flag’ advice and symptom management, as well as providing direct support with the activities of daily living in the absence of potential treatments. Maxwell and Radford assert that failure of the profession to reclaim nursing theory will mean that nurses will fail patients, unable to realise their potential to improve the lives of people with Long Covid.

Specialist community public health nursing during the pandemic

Specialist community public health nursing workforces (health visiting and school nursing) have had to meet the challenge of maintaining pre-pandemic services during repeated lockdowns, while also supporting colleagues in crisis, with mass redeployment to both community nursing and hospital services (Conti and Dow, 2020a; 2020b). Conti and Dow showed that up to 63% of full-time equivalent (FTE) health visitors across England were redeployed at some time between March and September 2020. Around 11% of local authorities lost one quarter of their FTE health visitors for an average duration of 67 days, leading to services stopping or significantly reducing to a near or complete virtual service in the first wave (although the move to virtual services was also influenced by reducing the opportunities for Covid-19 transmission).

At a time when children and families needed advocacy and education most, the service was at breaking point. This was recognised in October 2020, when a joint letter from Public Health England’s chief nurse, the chief nursing officer for England and the Local Government Association’s Community Wellbeing Board chair advised directors of nursing not to undertake similar redeployment strategies in consequential waves, and to consider health visitors and school nurses as frontline workforces (Lauder, 2020).

Eighteen months later, the longer-term consequences of the pandemic on children are becoming apparent. Specialist community public health nurses have become centrally important in the longer-term response with individuals, families and communities. They have a particular role in supporting those who are already disadvantaged, either through pre-existing disease, poor child development or through social deprivation such as homeless families (Dorney-Smith et al, 2020) through a progressive universal outcome-focused model, namely the

‘Universal in Reach – Personalised in Response Delivery Model’ (Public Health England, 2021). As part of Public Health England’s (2021) delivery model, specialist community public health nurses lead and use needs assessments to determine targeted intervention through four levels of service, including: community (signposting to community-based assets), universal, targeted and specialist levels of support. While health visitors and school nurses often see the majority of children, young people, caregivers and their families at specific times throughout childhood, such as developmental reviews as well as offering ‘drop-in’ universal services, these interactions provide opportunities for children, young people, caregivers and families to access a qualified clinician to co-produce solutions to health concerns. It is through this self-report and/or careful enquiry, through clinical questioning, by the health visitor or school nurse that Long Covid symptoms can be elicited.

Public Health England recognises that needs can change over time, so connectivity and fluidity is required between different levels of support, but most support for children and families will be met through the universal service offer, although the authors note a long-standing unwarranted variation of service offer to children and families across England due to different commissioning by local authorities (Institute of Health Visiting, 2020).

Co-producing child and family centred care through specialist community public health nursing

NHS England’s June 2021 plan for Long Covid (NHS England, 2021) included services for children for the first time, with 15 paediatric hubs alongside self-managed, community led and secondary care services for adults. The secondary care provision will have capacity for 68 000, suggesting that the majority of the almost 1 million people estimated by ONS to have Long Covid for more than 12 weeks will be cared for in the community and directed to online self-care products.

Community nursing services are not defined in the NHS England plan for Long Covid, but there are more paediatric specialists among community nursing than in the other community professions. Together with the expertise of specialists, such as health visitors and school nurses, nursing represents a huge but unrealised potential to meet the needs of children and young people.

Most of the evidence on Long Covid in children and adults has been descriptive, and uncertainties in our current understanding remain, with no clear treatment advice. Caring for individuals

Box 1. Applying the orientation to practice to children with Long Covid (Cowley et al, 2013; 2015)

Health creation/salutogenesis

Health creation is defined as the involvement of being proactive, and identifying and building on strengths and resources (both personal and situational) in clients' lives, through a focus on solutions. As Long Covid is an emerging long-term condition, specialist community public health nurses (SCPHNs) are in an optimal position to 'case find' those children experiencing Long Covid symptoms. In addition, children with Long Covid require a biopsychosocial assessment, focusing on both the problems as they experience them, and those identified through a systems-based (biomedical) model of assessment. Children with Long Covid require an individualised health plan that focuses on what they can do, what they cannot do and, more specifically, recognising the developmental challenges and the fluctuation of symptoms. Health creation also requires SCPHNs to understand the disease progression of Long Covid to identify red flags for medical treatment and health adaptation skills. Specific health promotion may be required for parents/caregivers in enabling them to care for their child with Long Covid, but the reverse will also be true, especially with parent/caregiver-reported child development and individuality of their child. SCPHNs will need to actively engage with multidisciplinary and multi-agency colleagues.

Human valuing/positive regard for others

Human valuing is defined as always keeping the person in mind and shifting the focus of clinical interactions to align with the needs of clients, while actively seeking out potential strengths through hope and recognising the potential for unmet needs. Children with Long Covid should not be considered for generic rehabilitation but be cared for through a co-produced, person-centred approach that requires individualised assessment and care planning to be symptom-led or titrated and based on risk assessment. Children reporting how they experience Long Covid should not be dismissed, may have been in other clinical interactions and should be encouraged to be open about how their symptoms change over time. Explicit collaboration with parents/caregivers is required to adopt a similar approach in their childcare practice and be appreciated in the context of the family.

Human ecology/person-in-situation

Human ecology is defined as the recognition of clients in their social and environmental situation. This recognition is achieved through continual process of assessment, while always taking account of the client's circumstances and how they operate in their social and environmental situations. Children with Long Covid may face further challenges beyond their presenting symptoms, and all assessments should be fully embedded within their daily activities as well as the impact that Long Covid has on their developmental maturity in recognising themselves in their own situations. Parents/caregivers should be empowered through additional community resources and referrals if the care of a child with Long Covid provides further challenge to their unique social and environmental situation.

with Long Covid is, therefore, based on managing symptoms, with the model similar to those for people with long-term conditions. Nursing models that focus on adaptation to changed health status and developing self-management strategies are of proven benefit in long-term conditions (Proctor et al, 2013). Perceptions of nursing theories and models are that they only suit the nursing academy in educational institutions (McCrae, 2012) and the work of translating them into tools for practice has not been done.

McCrae (2012) reiterated the need for evidence to be contextualised by practice expertise. Moreover, co-production approaches, already embedded in child health services, are essential in Long Covid, where the natural history is as yet unknown and those with lived experience gain understanding before researchers or health professionals.

Health visiting and school nursing should employ theoretical approaches to practice from the paediatric nursing literature, such family-centred care or partnership-in-care, to support children with Long Covid. Family-centred care can be defined as 'a strength-based relational approach to working in partnership with families caring for infants and children' (Ridgway et al, 2021: 1) but is often poorly implemented despite widespread endorsement by numerous professional bodies (Kuo et al, 2012).

A literature review by Kokorelias et al (2019) concluded that the conscious goal of family-centred care is to plan, implement and evaluate care of children through four main components: an explicit collaboration between family members and health professionals; a consideration of providing professional care in the context of families; a mutual learning of education provided by and between children, families and the health professionals; and ensuring that service policies and procedures support the implementation of family-centred care.

Health visitors and school nurses are ideally placed to respond holistically to children with Long Covid, and the associated impact of the pandemic on their families and communities. Cowley et al (2013; 2015) described the unique contribution of specialist community public health nursing as focusing on health creation (or salutogenesis), human valuing (or positive regards for others) and human ecology (or person-in-situation) rather than on a purest medical model of disease and cure. For children facing an uncertain future, this assets-based approach may reduce the anxiety associated with Long Covid by focusing on individualised plans to

maximise wellbeing in the present. *Box 1* explores how Cowley et al's orientation to practice can be applied to children with Long Covid.

Conclusion

Covid-19 has affected children in many ways, including Long Covid. They are frequently coping with a combination of different consequences of the pandemic, with many being the primary carer for parents and caregivers with Long Covid. While children rarely become acutely unwell with a Covid-19 infection, there is increasing evidence of Long Covid. Evidence from studies of adults, as well as case reports in children, show clear organic disease, although the exact causal factors are unclear. More research is needed to understand the risk factors, the prognosis and treatment.

Children with Long Covid live in communities experiencing the social, psychological and education impact of the pandemic, and it is unhelpful to separate out the different elements and to employ a medical model in isolation. Children with Long Covid and their families need help to navigate their way through uncertain times, health visitors and school nurses are well placed to support these families using theoretical frameworks from the paediatric nursing literature and Cowley et al (2013; 2015) orientation to practice in order to co-produce individualised plans. Specialist community public health nursing workforces are key to case-finding and co-producing person-centred care as well as contribution to the wider NHS.

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Key points

- ♦ Research on Long Covid in children is limited and there is a great deal of absence of evidence, rather than evidence of absence
- ♦ There is no international or national consensus on the case definition for Long Covid in children, meaning that sufferers may be missed by health professionals
- ♦ Long Covid is an emerging long-term condition symptoms in children, with symptoms including intestinal problems, pain and breathlessness, cognitive dysfunction and post-exercise malaise
- ♦ There is no standardised assessment, triaging, diagnostics or treatments for Long Covid, and the natural history of the infection is not currently known. The medical model is of limited use in this circumstance
- ♦ Health visitors and school nurses are ideally placed to case-find and co-produce child and family-centred care responses with children experiencing Long Covid

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