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The double invisibility of Long Covid in children

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ABSTRACT

The Covid-19 pandemic has been dominated by discussions of mild and short-lasting cases or acutely serious or lethal forms of the disease; less attention has been paid to long-term Covid-19 symptoms ('Long Covid'), particularly in children. This analysis of the experiences of children and adolescents with Long Covid, and those of their parents/caregivers, argues that children with Long Covid encounter a 'double invisibility' due to the condition's limited social currency and their status as the youngest members of society. We draw on 39 narrative interviews about children's and adolescents' experiences, conducted in 2021–2022 in the United Kingdom. The occurrence of Long Covid in children challenges key aspects of a dominant pandemic narrative, some of which have persisted from the early stages of the pandemic into 2023. Analysis of our qualitative interviews demonstrates that participant experiences were shaped and undermined by the convergence of three elements of the dominant pandemic narrative: that Covid-19 is mild, and everyone recovers; that children are not badly affected by Covid-19; and that worst of the pandemic was essentially 'over' as early as 2021/2022. In the face of these characterisations of Covid-19 experience, young people and their families reported significant additional challenges in making the illness experiences of children and adolescents visible, and thus in gaining appropriate support from medical and educational professionals. We interpret this in relation to 'social currency' - the extent to which an illness elicits understanding and acceptance by wider society. Children and adolescents with Long Covid struggled to signal the severity of their condition and elicit care in the manner expected for other debilitating illnesses. This was exacerbated by assumptions and stereotypes about unwell children and adolescents, and their parents, and questioning of their candidacy as reliable, trustworthy patients.

1. Introduction

Estimates suggest that there were approximately 1.9 million cases of Long Covid in the UK (2.9% of the population) in March 2023 (Office for National Statistics, 2023), and over 65 million globally (Ballering et al., 2022), although this is likely to be an underestimate due to undocumented cases, particularly since policy changes on testing and monitoring Covid infection rates. Despite this, until recently relatively little attention focused on longer-term and chronic forms of Covid-19, with early pandemic narratives dominated by the number of cases, hospitalisations and deaths, and the development of vaccines. Early awareness of the long-term effects of Covid-19 was patient-led; Callard and Perego (2021) describe Long Covid as 'the first illness to be collectively made by patients finding one another through various social media' (p. 2), often in the face of dismissal of experiences of sometimes bizarre and fluctuating symptoms by healthcare professionals and members of the public.

Although the prevalence of Long Covid is thought to be highest in those aged 36–50 years, it does occur in children (Davis et al., 2023), with estimates of up to 25% of infected children affected (Lopez-Leon et al., 2022). While attention to the long-term effects of Covid-19 has evolved, for example, with debates over whether Long Covid should be characterised as a disability, allowing access to welfare benefits (Hereth et al., 2022; O'Brien et al., 2023), the condition continues to occupy limited space in both public consciousness and health system priorities.

This article proposes the term 'social currency' to describe the extent to which an illness experience elicits understanding and acceptance by wider society. This term as been used by economist Erich Joachimsthaler and colleagues , who used the term to describe the level of influence an individual or brand has in convincing others to identify with a particular

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brand (Lobschat et al., 2013). The concept aligns with notions of social capital (Bourdieu, 1977), but rather than referring to the resources one has available to them (capital), it is about the 'going rate', or leverage, of those resources (currency). At the time of the study, the shared meanings and representations of Long Covid meant that the claim that children could or were experiencing Long Covid had limited social currency (described by Ireson and colleagues in relation to Long Covid in adults as low 'disease prestige'). At the time, although ideas about Covid-19 and Long Covid were evolving and often contentious (Jaspal and Nerlich, 2023), there was a view that children were at less risk from catching Covid and could overcome it more readily (Smith et al., 2022).

In this article we propose that Long Covid, perhaps due to its recent emergence as an illness with an (as yet) unknown prognosis, holds little social currency in comparison with other chronic diseases which severely impair people's day-to-day lives (Au et al., 2022; Roth and Gadebusch-Bondio, 2022), particularly for children and young people. This is enhanced when externally visible or tangible symptoms are absent or episodic, rendering the person's disability with Long Covid invisible, along an impairment continuum (O'Brien et al., 2023). The lack of visible symptoms, coupled with the current absence of biomarkers and medical tests to definitively detect, diagnose or monitor Long Covid, results in patients being unable to engage in what we term here 'severity signalling' (the ability of people to communicate the severity or extent of their illness to others) and thus presents barriers to communicating to others the extent to which Long Covid constitutes serious illness and disability (Maclean et al., 2023).

For a range of socio-political reasons, Long Covid has also been relatively invisible in terms of policy priorities, and had received little attention during the data collection period. While changes in global Covid-19 policies partially reflect particular phases of the pandemic in terms of rates of cases, hospitalisations and deaths, they may also reflect a collective longing during the early years of the pandemic for the it to be 'over' and so stories that raise the prospect of the Covid-19 pandemic's ongoing and long-term impact may be unwelcome. Howell (2022) suggests that Long Covid narratives are distinct from a linear 'crisis to cure' narrative, or, in this case, 'pandemic's start to pandemic's end'. In elucidating different forms of illness narratives, Arthur Frank theorises that those whose chronic illness experience can best be described as a 'chaos' narrative are essentially prevented from telling their stories because they include neither happy endings nor triumphant resolutions (Frank, 1995). Not recovering from Covid as expected was perhaps seen as 'spoiling' a widely accepted pandemic lay narrative.

Early narratives in 2020 around the prevalence and transmission among children strongly downplayed their risk of contracting Covid-19 at all, and more so the possibility of serious or lasting illness resulting from infection in children and adolescents. The increased risk of serious illness with increasing age was an important part of preventive strategies, such as the priority for roll out of vaccinations. However, this reinforced the narrative of the relative invulnerability of the young and contributed to the invisibility of children at this stage of the pandemic. The recent report of Child-related Policies in the First Year of the COVID-19 Pandemic in 40 Countries reinforces this, suggesting that children and families were not widely prioritised in public policy during the height of the pandemic (UNICEF, 2023).

The absence of policy focus on Long Covid by social and political institutions has had implications for education, workplaces, and patients' ability to seek care (Maclean et al., 2023). These strong messages from the very early phases of the pandemic (in 2020) have persisted over the following years even as evidence has evolved. Despite this, children have received little attention in the medical literature and policy agendas, with patient advocacy groups playing a crucial role in raising the profile of the disease (McFarland et al., 2022). Thus, children with Long Covid have their contested illness status compounded by their societal status as children.

A significant body of work (Alderson, 2007; Alderson and Morrow, 2020; Mayall, 2002) has contended that children's positioning in the generational social order within medical contexts positions them as unreliable, pre-citizens with compromised agency and argued that children's views must be taken seriously. However, this was not what our participants report experiencing in encounters with many healthcare professionals, teachers, and peers. In this article we argue that children with Long Covid endure a 'double invisibility'. Long Covid's lack of social currency, coupled with increased difficulty of 'severity signalling' in comparison with better understood conditions, has rendered Long Covid invisible in much of the public consciousness. Children then face an additional layer of invisibility given their presumed low-risk, further fuelled by deep-rooted stereotypes about children and adolescents who are unwell with poorly defined illnesses, and their parents (Loades et al., 2021).

In this paper, we use the notion of 'narratives' in the more lay sense, as the types of stories that people tell each other and have used to collectively construct ideas about the pandemic, rather than to indicate use of a narrative method of analysis. We draw on the notion of collective representation (Durkheim, 1971), the idea of assemblage of symbols, meanings, and ideas that are external to the individual and yet permeate and shape illness experiences. Collective patterns of thought shape experiences of illness and sickness (Herzlich and Janine, 1987). We identify three such prevailing patterns or representations in our data, following the earliest phases of the pandemic in 2020 in the UK: that Covid-19 is mild and (almost) everyone recovers; that children are not badly affected by Covid-19; and that the worst of the pandemic was essentially over by 2022. The convergence of these patterns in participant stories about their illness experiences demonstrates how Long Covid in children is perceived to be largely invisible to much of society.

2. Methods

This paper draws on interviews collected as part of the NIHR-funded 'Understanding Long Covid in Families' study. An advisory panel, including patient and public involvement (PPI) representatives with lived experience of Long Covid or of caring for a child with Long Covid, had input into all aspects of the study conduct, including the interview topic guide and recruitment methods. The interviews included in our analysis were undertaken between October 2021 and July 2022 using a narrative and semi-structured interview approach (Ziebland et al., 2021).

2.1. *Data collection & sampling*

We aimed for maximum variation sampling (Coyne, 1997), with diversity in age, gender, ethnicity, geographical location, and socio-economic status across the United Kingdom. Participants included both *patients* who had experienced Long Covid themselves, and *family carers* for someone with Long Covid. Recruitment was via several routes to capture diversity in experiences, including through social media, patient support groups, clinicians, community groups, and snowballing. After receiving information about the study and the opportunity to answer any questions, participants gave recorded verbal consent to the interview. Those under 16 years provided assent and their parent/caregiver gave proxy consent on behalf of the child/teenager.

The interviews were conducted remotely via online video platforms or over the phone, and were audio or video recorded depending on participant preference. Interviews typically lasted 60–90 minutes; several were shorter in length or conducted over several sessions to accommodate participant fatigue, other Long Covid symptoms, medical appointments and educational commitments. The semi-structured interviews began by asking participants to recount their illness (or their child's) experience to date, and the second part of the interview asked follow-up questions, including how they first came to understand that they (or their child) had Long Covid, the impact of Long Covid on family life and their experiences of other people's responses to their condition.

Participants were given a £30 voucher to thank them for sharing their time and experiences. Ethical approval was granted by Berkshire Ethics Committee REC Ref 12/SC/0495.

2.2. Data analysis

The interviews were independently transcribed, checked for accuracy, de-identified and imported into nVivo (version 1.6.1) to organise the data; interviews were grouped on the basis of participant category (children and adolescents with Long Covid, or parents/caregivers who were caring for a child or teenager with Long Covid). We developed a coding framework based on interview content which was refined through discussion with all authors. A team of researchers (R1, R2, R3) coded the transcripts. The data were analysed conceptually using the mind-mapping ('OSOP') technique developed by Ziebland and McPherson (2006), allowing for connections to be made across the data as well as identifying outlier cases. Illustrative interview extracts are presented here to represent the scope and landscape of the dataset.

3. Results

In this paper, we included 39 participants, comprising: 22 children and adolescents aged 10 years or older with Long Covid (14 female, 8 male), and 17 parents/caregivers, 11 of whom were caring for a child or young person with Long Covid (10 female, 1 male), and six who both had Long Covid themselves *and* were caring for their child with Long Covid (5 female, 1 male) (Table 1). This analysis interweaves the experiences of children and adolescents with Long Covid from their own and their parent/caregiver(s)' perspectives. We suggest that, in the UK, collective representations ('narratives') of the pandemic, as interpreted by participants, were shaped by the convergence of three strands of the narrative that dominated from the outset in 2020 or developed as the pandemic progressed, which were felt to undermine participant experiences of having a serious and debilitating illness. These strands are: that Covid-19 is mild and (almost) everyone recovers (3.1); that children are not vulnerable to or badly affected by Covid-19 (3.2); and that the worst of the pandemic was essentially 'over' by 2022 (3.3). In the face of these perceived characterisations of Covid-19 experience, which were largely at odds with participant experiences, children, adolescents and their parents encountered significant challenges in making their illness experience visible. Many of our participants were initially infected in the early stages of the pandemic in 2020 and 2021, in the context of limited scientific knowledge and established treatment pathways, and before widespread availability of testing. We elaborate on how Long Covid's lack of social currency coupled with the difficulty of effective 'severity signalling' and prevailing stereotypes about unwell children and their parents, contributed to participants' inability to gain traction with their peers, social circles and healthcare professionals. In doing so, we move between public to private accounts (Cornwell, 1984) of Long Covid and

Table 1
Participant characteristics.

Participant ID	Age of child with Long Covid	Participant Gender	Participant Ethnicity	Parent or caregiver age	Month caught Covid	Month interviewed
Children with Long Covid						
Jared	16	Male	White British	–	December 2020	November 2021
Jack	12	Male	White British	–	March 2020	December 2021
Arthur	12	Male	White British	–	Spring 2020	December 2021
Roisin	16	Female	White British	–	September 2021	December 2021
Billy	14	Male	White British	–	December 2020	February 2022
Maggie	11	Female	White British	–	July 2020	March 2022
Lily	14	Female	White British	–	September 2021	March 2022
Brianna	10	Female	White British, Japanese, Italian, Brazilian	–	January 2022	March 2022
Emelia	15	Female	White British	–	September 2021	March 2022
Joanna	16	Female	White British	–	August 2020	March 2022
Alice	13	Female	White British	–	July 2021	April 2022
Leah	14	Female	White British	–	July 2021	March 2022
Hugo	13	Male	White British	–	September 2021	April 2022
Amir	12	Male	Slovak, Algerian	–	September 2021	May 2022
Aisha	15	Female	Pakistani	–	July 2021	June 2022
Emily	14	Female	White British	–	November 2021	June 2022
Zoë	12	Female	White British	–	May 2020	June 2022
Zainab	16	Female	Pakistani	–	September 2021	June 2022
Yasmin	17	Female	Pakistani	–	September 2021	June 2022
Salma	13	Female	Pakistani	–	January 2022	June 2022
Fuhad	12	Male	Pakistani	–	January 2022	June 2022
Dina	11	Female	Pakistani	–	September 2021	July 2022
Parents of children with Long Covid						
Margaret	16	Female	White British	53	December 2020	November 2021
Patrick	16	Male	White British	47	September 2021	December 2021
Bianca	6	Female	Mixed	42	May 2021	March 2022
Rebecca	8	Female	White British	Not stated	November 2021	April 2022
Kirsty	10	Female	White British	42	January 2022	March 2022
Renee	4	Female	White British	41	March 2020	April 2022
Genevieve	10	Female	White British/Manx	36	March 2021	April 2022
Maeve	10	Female	White British	40	October 2021	April 2022
Anita	11	Female	White British	39	October 2021	April 2022
Maria	12	Female	Slovakian	50	September 2021	May 2022
Jada	6	Female	Caribbean	38	February 2022	June 2022
Parents of children with Long Covid (and have Long Covid themselves)						
Rachel	8	Female	Ashkenazi Jew	39	March 2020	November 2021
Clara	12	Female	White British	48	March 2020	December 2021
David	13	Male	White British	49	March 2020	December 2021
Olivia	4	Female	White British	50	March 2020	January 2022
Leila	12 & 13	Female	Pakistani	Not stated	December 2021	June 2022
Simran	11, 16, & 17	Female	Pakistani	48	September 2021	July 2022

the Covid-19 pandemic more generally.

3.1. *"Covid-19 is mild and (almost) everyone recovers after a short illness"*

The first strand of the dominant pandemic narrative that undermined participant experiences was the belief that Covid-19 infections were mostly mild (increasingly so as the pandemic progressed, and hospitalisations decreased) and that infections would resolve quickly. In our data, participant experiences were underpinned by their awareness of the persistent messaging in public health and news bulletins which focused on deaths and hospitalisations as outcomes of Covid infection. The focus on apparently binary outcomes of Covid infection, particularly in the early stages of the pandemic – death or survival, hospitalisation or a 'mild case' – did not leave space for the varying degrees of morbidity and disability experienced by people with Long Covid. As one mother whose 8-year-old child had Long Covid symptoms (and who had Long Covid herself) said, "*everybody tells you Covid is [over] in two weeks, unless you're elderly and then you are in the A&E, in the ICU. That's it, there are the options. Nobody knew there are other options available*" (Rachel, interviewed November 2021). Similarly, a GP who had Long Covid, and whose 13-year-old son also had it, expressed the view that there was a lack of understanding of the illness amongst the general public:

> The whole British public don't get it. It's, sort of, be talking about death, it's almost this bottomless – either, you know, you're either alive or you're … you're dead, and it's nothing to do with like, you know, people don't seem to understand about the Long Covid situation. – David, interviewed December 2021

Overall, participant accounts were marked by the distinct lack of social currency of Long Covid. It was sometimes difficult for people to articulate their own Covid experience when it diverged so far from the dominant collective stories being told at the time, at least as perceived by participants. This was especially challenging for children and adolescents with Long Covid and their parents/caregivers, given the widespread messaging in the first few months of the pandemic that Covid-19 was generally a mild illness and not easily transmissible by or to children.

> What's really frustrating is hearing people talk about, you know, "it's only mild, it's this or it's that," and you're going, "What, you, you have no fucking idea […] you have no idea what it's going to be like; we just don't know." – Patrick, interviewed December 2021, father of 16-year-old with Long Covid

Teenagers Emelia and Jack said that they did not like to talk to their friends and peers about their illness as *'they wouldn't understand even if … even if they tried to, and a lot of the times they'll just like make a joke out of me not being able to taste things*" (Emelia, 15-year-old). Other teenagers or parents of children with Long Covid described having their credibility questioned.

> I don't really tell [others at school] because I know they will just take the piss […] they know that I've got Long Covid, but they don't really care and, and they kind of like pick on me for it. So, like, "Oh you're just trying to get off school." – Jack, 12-year-old with Long Covid, interviewed December 2021

> Other people, again, similar: "Does Long Covid even exist? Is it even a thing?", you know, "Is it not just that she would have been poorly anyway?" Not really understanding that Covid can do this and that she hasn't really recovered, like maybe I'm overreacting, you know … - Genevieve, mother of 8-year-old with Long Covid, interviewed April 2022

Not only was there widespread lack of understanding among the general public, for many participants, there was a persistent perception that those they spoke to would judge them to be 'overreacting', contributing to a persisting invisibility of Long Covid among adolescents.

Because of this public rhetoric described by participants, they subsequently found it difficult to engage in what we refer to as 'severity signalling', by which we mean the ability of people to communicate the severity or extent of their illness to others. It was challenging for people with Long Covid to severity signal in the same way that is possible with illnesses that are more visible and are more widely understood socially and culturally to be 'serious', with associated cultural scripts. One mother of a 10-year-old contrasted Long Covid with the reaction they expected to follow a cancer diagnosis, saying *"people know what the pathway for cancer might be" (Maeve, interviewed April 2022),* suggesting that cancer is widely understood to be grave or significant. People recounted that disclosures of Long Covid seldom invoked empathic responses or recognition of its seriousness among participants' social circles or in healthcare settings.

The lack of definitive biomarkers and diagnostic medical tests for Long Covid was particularly problematic, because participants felt unable to provide irrefutable evidence of their illness to those who questioned or challenged them. Several participants described how 'on paper' there was nothing 'officially' wrong with them. Those who could provide some 'proof' (in Genevieve's case, with an X-ray that showed that her child had lung damage), said they were able to access help more effectively.

> When [children are] really ill sometimes, they're just accused of being difficult if [healthcare professionals] can't measure what's going on. I think that's the problem as Covid is throwing up immeasurable things. – Maeve, mother of a 10-year-old with Long Covid

> It's just like a weight lifted off your shoulder because you … you know, I know there's something wrong with her, but when you can't get anywhere, you … you sometimes almost think, "Am I seeing something that's … that's not there?" […] but to … to see the chest X-ray and there be an issue, you're like, "Ahhh, finally …", you know, it's that kind of relief that you haven't been making it up this whole time, and you can start to move forward and … and her be able to get the help and support that she needs, rather than just almost on a treadmill backwards and forwards not getting anywhere, so she … you know, she's not getting the help and support for her needs. – Genevieve, mother of an 8-year-old with Long Covid

This, coupled with the unpredictability, variability and episodic nature of their symptoms (O'Brien et al., 2023; Maclean et al., 2023), meant that participants experienced difficulty communicating the legitimacy of their illness or impairment, against a perceived collective pandemic story that largely ignored sustained morbidity as a valid outcome of Covid-19.

3.2. *"Children don't get Covid-19"*

> "Well look, [David], kids don't get Covid, chances are it's just another virus and you're just anxious, go home," and just discharged us and stuff, and then no follow up. - David, GP, father of a 13-year-old with Long Covid, who also has Long Covid himself, interviewed December 2021

Qualitative studies of adults with Long Covid have highlighted the extent to which they felt unheard or invisible in the early stages of the pandemic (Maclean et al., 2023). This invisibility was substantially exacerbated for children and adolescents with Long Covid, due to a dominant second strand in collective pandemic narratives as articulated by the participants – that children were 'not affected' by Covid-19. Some participants maintained that the invisibility of children, or the active framing of children as at low risk of *acute* infection, particularly in the early stages of the pandemic, meant the perceived risk of children developing a *significant and long-term* illness was minimised. Even when children were more central in debates around infections in schools, this public perception of children as low risk for long term disease persisted:

> At the beginning of the pandemic, it was clearly the older people and people with diabetes and high blood pressure and so on that were more vulnerable to severe disease […] it's certainly not something which is benign in children. And if we hadn't had so many adults dying and being so unwell with it, I'm sure the focus would be entirely different. […] I think it's something which has been played down quite a lot and not always taken into account in the decisions that have been made about how it's all been handled. - Margaret, mother of 15-year-old with Long Covid, interviewed December 2021

> [The nurses] kind of said, "Oh yeah, no, we've heard about Long Covid but we didn't think it happened in children." We've had that so many times. I think because [when] Covid was in the very early stages it was, "Children don't catch Covid and things like that." And then, suddenly, children started coming down with it. I think they've kind of been forgotten – Rebecca, parent of 8-year-old with Long Covid, interviewed April 2022

Children had also thought they would be unlikely candidates for 'long-term' effects from Covid. One teenager said that before she became ill, she had never considered the possibility of getting Long Covid "*especially in children. I thought maybe like adults would have more like long-term effects and [when] I heard that children have it as well, I was like, okay, that's kind of interesting*" (Zainab, 16-year-old with Long Covid).

Children's experiences suggested a deep-rooted sense of disempowerment; their credibility as Long Covid patients was challenged by their reduced capacity both to *articulate* what was wrong with them and to *advocate* for themselves (and therefore sufficiently signal severity).

> Yeah, there are times where she said, "People don't believe me, people think I'm making it up," so she can get quite upset. She's … she's a very resilient child though, so she will just kind of get up and get on with it and keep going. She has her moments of you know being upset and she'll say, "Oh Mum, no-one … no-one's playing with me today because they don't believe me, they think I'm making it up, they think I'm saying things that are not true," but said, "but Mummy, I can't breathe," I'm like, "I know, it's okay." – Genevieve, mother of an 8-year-old with Long Covid, interviewed April 2022

For older children and adolescents, this was sometimes compounded by a reduced physical and/or cognitive capacity that is a common symptom of Long Covid. However, parents who advocated for their young children with Long Covid also suspected that their own credibility was being questioned:

> And I think for kids, when they can't tell you what they're feeling, it is so difficult, and up until now, you know, it has been hell really for us to even try and gauge, you know, what he's been going through […] when I've been his voice, sometimes I've felt like people have thought, like, "she's got Munchausen's by proxy [where a caregiver makes up or exaggerates symptoms for others in their care], you know, she's just saying that he's feeling this or feeling that", and they think that I'm a mad mother, but the only reason I'm doing it is because I feel like I'm the only person that can know what he's been going through, and now he's verbalising those things, like his pins and needles, you know, I know what the pins and needles feel like because I've had the pins and needles, I've got the pins and needles [since having Long Covid]. – Olivia, mother of 4-year-old with Long Covid, also has Long Covid herself

The presumed absence or rarity of Long Covid in children combined with the lack of currency of Long Covid meant that children stood at the hinterland of candidacy for Long Covid recognition and healthcare (Maclean et al., 2023), which became an increasingly distant, marginalised territory. Conversations with health professionals who could affirm their candidacy could be extremely fragile. This was especially apparent in accounts of how (parents of) children in such a precarious position described their conversations with health professionals. For example, David, a GP, said that the way the pain clinic team dealt with his 13-year-old son's symptoms was 'just vile' and 'patronising'.

> They were really condescending, they talked to him like he was, like, a seven- or eight-year-old, you know, it was just in baby language and everything else, and it just made things worse, I mean, it basically made him suicidal […] my son was going on about her going, "I hate talking to that woman, she just makes me feel like a baby, treats me like a child and just keeps going on about how great she is," and they did nothing but make him a million times worse. – David

David's account of his son's experience is illustrative of children both perceived and interacted with as occupying a lower social status. Talking to peers and health professionals about children's experiences of Long Covid was thus extremely difficult for participants when they felt they had to contend with the wider invisibility and lack of social currency of Long Covid, coupled with an intensified invisibility of children.

3.2.1. *Presenting symptoms of long covid against the backdrop of stereotyping 'unreliable adolescents' and 'overprotective' parents*

Despite a significant research literature on experiences of illness and disease amongst children that recognises the rights, views, and agency of children and adolescents (See Alderson (2007, 2008) and Alderson and Morrow (2020)), there remains a trope amongst health professionals and popular media of children as vulnerable and lacking in agency or ability as competent actors. Adolescents in our sample appeared to also contend with a perception of them as 'unreliable narrators' of their own health stories. Their accounts of seeking recognition for their Long Covid symptoms suggested that their experiences were commonly interpreted against a perceived backdrop of widespread stereotypes of adolescents as lazy, self-centred, temperamental, and 'going through a phase'; furthermore, young women felt they were perceived as over-dramatic, hormonal or anxious. These stereotypes were particularly evident throughout participant accounts of their interactions with health professionals. For example, Joanna, a 16-year-old girl with Long Covid, said she was told by a GP that her symptoms were due to anxiety, "*in [her] head*" and from being on her phone too much. Another girl, whose symptoms imposed severe restrictions on her day-to-day life explained that her paediatrician had downplayed her symptoms and compared her unfavourably to other people:

> He was saying I was being dramatic. He compared me to a girl [who] had lost her ability to walk. She was in a wheelchair. She was paralysed. And he was kind of, he was comparing my problems to hers. And, like, they're two completely different things. – Leah, 14-year-old with Long Covid

Some participants attributed this dismissal to health professionals' inability to explain, manage or treat their debilitating symptoms, and so relegating them to the psychosomatic realm in the absence of any other explanation. David, a GP himself, remarked:

> Some of the doctors will go, well okay, well, if they don't know what it is, it's anxiety, and that's what it is, so basically well, all the symptoms, because it's a multisystem – "It can't be real, it's got to be all coming from your head and you're making it all up" type of situation – David, father of a 13-year-old with Long Covid

> Similarly, Margaret commented:

> I think there's also a lot of people who kind of psychologised it. So, instead of looking, looking at a patient and wondering why suddenly this 16-year-old's gone from sprinting up mountains on a bike to not being able to get up the stairs, they are being told that he needs to see a psychologist […] The symptoms don't fit into an easy box with a label. And doctors tend to put it into whatever box they know that

> seems to fit, which might be anxiety or chronic fatigue syndrome or something like that. – Margaret, mother of teenager with Long Covid

As in the example above, several participants resisted the implication that adolescents with Long Covid were simply trying to get out of doing things (Maclean et al., 2023). They emphasised they had lived full and active lives before becoming unwell. Yet Emelia said that her friends thought her "lazy" because she needed a lift home from school instead of walking. Aisha thought her friends *"think that, like, I'm just not going to school because I don't want to [...] I liked going to school, like, I never had a problem with it." (Aisha, 15-year-old with Long Covid).* David resisted the idea that his 12-year-old son was a "hypochondriac", emphasising that before getting Covid his son was "mega fit" and enjoyed playing lots of sports.

> … they think you're just probably making it up, but when you sort of say, "Well, my son's been going though it as well," you know, and he's an 11-year-old, 12-year-old, they're not going to be hypochondriacs and making things up like that when [he is] mega fit, you know what I mean? - David, father of child with Long Covid

Despite such assertions of evidence of the reality of Long Covid, adolescents reported feeling dismissed and sometimes denied care, making it difficult to resist this minimisation, and their treatment as 'unreliable' candidates for Long Covid (Au et al., 2022), which some referred to as 'gaslighting'.

Despite not having to contend with the supposed unreliability of youth, comparable stereotypes were also demonstrated in parents' accounts of their challenges in advocating on behalf of their children against the backdrop of an uncertain illness. Parents reported feeling like they were seen as overprotective, irritating worriers. One reported her daughter's doctor had "accused" her of suggesting "*nut job sort of crazy stuff that [she had] learned from [a patient support website]*" (Joanna's mother, mother of 16-year-old with Long Covid). Another parent, having spoken independently with and been reassured by "*a really well-regarded clinician at a hospital in London*", said that she "*daren't tell the doctors that* [laughs]*, because they already think I'm this academic who's trying to diagnose my daughter and ignoring medical advice, although we've not really had any [medical advice]*" (Kirsty, mother of child with Long Covid). Similarly, Maeve reported feeling that she was perceived as being 'over-reactive' despite the severity of her daughter's illness.

> [There was] a sense of not being believed that she was ill, that I was being an over-reactive mother, that she wasn't that sick, when she was, and she's described as one of the most severe Long Covid cases by the doctors I'm speaking to who have [treated] Long Covid children. – Maeve, mother of child with Long Covid

Other health professionals were reported to have implied that perhaps Long Covid was a 'fad' – "*an overreaction, a 'jump on a train', like everyone's talking about Long Covid, let's jump on their Long Covid train*" (Genevieve):

> [The doctors said] "don't worry about it, she'll be fine, she just needs time to get over it, Long Covid's a bit … well, you know." That was kind of almost the attitude of it … that it didn't really exist so … although it wasn't said in … in … in that many words, it was insinuated that Long Covid was just a term people had … had picked up and actually this was not, categorically, was not what … what was wrong with my daughter. – Genevieve, mother of 8-year-old with Long Covid, interviewed April 2022

One parent described how, after a psychiatrist dismissed their concerns, saying "*Get going and get home!*", she became "*hardened*" and less sympathetic towards her daughter. Several participants were concerned about others thinking they had Munchausen's syndrome by proxy, such as Olivia, referenced earlier, and David, who reported:

> "I even spoke to the paediatricians and said, "Look [er] I mean, there was quite a lot of symptoms there and I don't want to come across like I'm a complete nutter of a patient" […] I was coming in as a major somatising [sic] disorder by proxy, like, I was getting worried and eventually, over the whole of last year it did cross my mind that, "Am I going to be investigated by the Social Services for Munchausen by proxy?" [laughs] […] the thing was, fortunately [my son] was in a hospital in agony and with all these symptoms that [the paediatrician] could see that, you know, that we weren't making it up, but you just start having these strange thoughts when you're at home and you've got nothing else to do, because you're not working, and you start worrying that "Am I coming across as that as a parent?", you know, and that that sort of thing obviously did cross my mind." – David, father of a 13-year-old with Long Covid

This awareness and concern about Munchausen's syndrome by proxy demonstrates the ways in which parents reported feeling like they walked a fine line between presenting themselves to healthcare professionals as a responsible parent who is concerned about and advocating for their child, and being seen as an unstable, overprotective and over-anxious parent. Parents balanced the strong felt need to signal severity, with not coming across as a 'mad mother' (Olivia), or 'complete nutter of a patient' (David). Long Covid's lack of social currency exacerbated this.

Overall, parents grappled with combatting the persistent idea that Covid-19 did not affect children, alongside common disparaging stereotypes about adolescents (and parents), at times even questioning their own legitimacy.

3.3. *"Covid-19 is over"*

> There seems widespread denial of Long Covid's existence rather than meaningful conversations. – Maeve, mother of 10-year-old with Long Covid, interviewed April 2022

As lockdowns and other preventive measures began to abate, Long Covid also received poor social currency because it threatened another (hopeful) strand to dominant pandemic narratives that 'Covid-19 is over'. Although there were gaps in knowledge about Long Covid and its effects – more so in earlier stages of the pandemic – our data suggest people affected directly by Long Covid perceived a wilful ignorance amongst a wider public who did not want to engage with it. One participant, whose partner and child both had Long Covid, said "[Long Covid is] *an underlying issue that no-one wants to face, and that it will just go away, it feels like it will just go away, people will get better and it will go away."* (Renee, mother of 4-year-old with Long Covid and whose partner had Long Covid, interviewed April 2022).

People who deviated from the social expectation of all but the most vulnerable recovering quickly after infection with Covid-19 reported feeling like they were treated with suspicion. For example, one 11-year-old who had caught Covid several times and developed ongoing symptoms recalled how her peers had questioned her reinfection, saying, *"I feel like [people said] "Why you've had Covid twice?" Quite a few people were staying a bit away from me because I had Covid twice." (Dina, 11-year-old, interviewed July 2022).*

Some people reported encountering indifference or irritation when they spoke about their Long Covid symptoms. Emelia, a 15-year-old with ongoing symptoms, described how she avoided bringing up her illness in conversation with her friends because it 'annoyed' them, saying, *"it's easy for them to get annoyed when I bring it up once in a while because they don't have to think about it 24/7, you know?" (Emelia).* Bianca also recounted, in strong language, experiencing indifference, dismissal and irritation from her child's school, which appeared unaccommodating:

> *The attitude was, "Yeah, well, most people are fine, so fuck off," [laughs] basically […] I felt like they were saying … "Yeah, but you're just like one weird family that have got, you know, a … a weird child who's remained a bit sick," like, "Most people are absolutely fine, so why should we*

> *consider the freaks who don't get better within a few [days]?" – Bianca, mother of 6-year-old with Long Covid, interviewed March 2022*

An incomplete recovery from Covid was moralised and participants reported feeling reproached for 'spoiling' the narrative that the pandemic was (almost) over. Alice (13-year-old) said she did not mind explaining what was wrong to people who were 'respectful' of her experiences, but she felt admonished by other people for her lack of prompt and full recovery. She added, *"if someone's just, like, not being very polite about it, like it's a … you don't really want to talk to them because they're basically telling you off for something you can't control"*. Similarly, Rachel said people seemed 'disappointed' in her and her 8-year-old daughter for not recovering in the 'expected' manner:

> People are surprised to hear you are not okay, people are disappointed with you not doing all the things you should be doing. People are also like, "Really? Covid, you know this disease of elderly people, or … ?" You know, or "Some people had Covid and they're fine," so you're very looked upon like in a weird way. And again, you don't have any clinical proof of your condition. – Rachel, mother of 8-year-old with Long Covid, who has Long Covid herself, interviewed November 2021

Some people articulated a tension between the desperation for recognition and the fear of "backlash" if they challenged this aspect of the dominant pandemic narrative. For example, Olivia said, *"while I want to scream from the rooftops about his [son's] illness, I'm very conscious that I don't want to ram it down people's throats."* However, analysis of participant accounts showed that some actively defied this public narrative by reminding people that not everyone recovers quickly from Covid. For example, 13-year-old Alice said, "*people need to know about these kinds of things because it's new, and like, if people don't know about these things, how are we going to learn about these things, you know?"* Similarly, Bianca recounted mentioning that her six-year-old daughter had not fully recovered from Covid, and that she was struggling with symptoms several months later:

> Part of me really, really wants to keep reminding people that this thing exists, when it's very convenient to pretend it doesn't, or to not think about it because it's depressing and inconvenient. So yeah, sometimes I'll just … I'll put it out there because I think someone needs to know [laughs], someone needs to be reminded that kids aren't all … you know, when, for example, people are taking a very light-hearted approach to Covid, 'Oh, ha ha ha ha, I tested positive, oh my God, it's just like a mild cold though," […] when someone is being too light-hearted about their positive test, I'll maybe throw in that my daughter has been suffering for nine months and has developed a heart murmur and she's six years old, and, you know, that probably feels very uncomfortable for people, but sometimes when you … I make a judgement that some people need reminding. – Bianca, mother of six-year-old with Long Covid, interviewed March 2022

Both examples above demonstrate participants' attempts to counter this strand of the pandemic narrative within their social circles by challenging their peers' and colleagues' perceived ignorance of ongoing Covid-19-related illness.

4. Discussion

In this paper, we demonstrate that children with Long Covid have experienced a 'double invisibility', owing to the lack of social currency of Long Covid in general, compounded by children's status as 'unlikely' candidates. While a lack of available diagnostic tests and frequently invisible or episodic symptoms often limited people's ability to convey the severity of their condition and elicit appropriate empathy and care, as reported elsewhere for adults (Ireson et al., 2022; Maclean et al., 2023; O'Brien et al., 2023), prevailing stereotypes also questioned the reliability of adolescents (and even their parents) as narrators. We suggest that, in the UK, collective representations of the pandemic were shaped by the convergence of three strands of a dominant narrative that undermined and was at odds with their lived experience: that Covid-19 is mild and (almost) everyone recovers; that children are not badly affected by Covid-19; and that the pandemic is essentially over. The existence of Long Covid in children and adolescents threatened this dominant pandemic narrative that persisted through the duration of participant experiences.

At the time of writing, to the best of our knowledge, there are few qualitative explorations of the experiences of children and adolescents with Long Covid and their parents/caregivers. However, there are striking similarities with accounts of stigmatised (Byrne, 2022) illnesses such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and other contested conditions, also characterised by episodic symptoms (O'Brien et al., 2023), uncertainty, de-legitimisation, and felt and enacted stigma (Scambler, 2004). For example, although CFS has been a defined diagnostic entity for over thirty years, children with CFS and their parents still 'report feeling misunderstood and disbelieved by medical and educational services' (Loades et al., 2021). Children with sickle cell disorders deal with minimising and de-legitimisation from teachers and peers, thereby '[draining] the somatic, cultural and social capital of adolescents living with sickle cell' (Dyson et al., 2011). Similarly, a study of juvenile arthritis found that children avoided telling others about their condition, described by the author as an invisible illness (Guell, 2007).

Uniquely to Long Covid, however, is a protracted consequence of an infection (Covid-19) that diverges from concurrently developing collective representations of the pandemic. Having exceeded their accepted stay in the 'kingdom of the sick' (Sontag, 1978), participants recalled provoking a sense of disappointment from healthcare professionals, teachers and peers in response to disclosure of their continuing Covid illness. Society's low tolerance for illnesses that do not resolve and/or defy explanation (Dumit, 2006; Jutel, 2010) means that encountering the experiences of people with Long Covid can be jarring, challenging, and disturbing – a threat to society's collective 'triumph' over Covid-19. Arguably, this privileges a societal investment in the continued invisibility of Long Covid in much of the public's collective consciousness. In this way, Long Covid – particularly in children – became what Frank termed as a threat for the collective (Frank, 1995). With no clear promise of a restitution narrative (where illness is temporary and overcome), the remaining chaos illuminates and reminds us of our own embodied frailty, which can be difficult to listen to (Nettleton, 2006). This is especially the case in relation to children, who are generally expected to embody health, energy and vitality. This paper therefore creates space for the voices of children and their parents, whose stories may not be well-heard because they '[bring] the listener's bodily contingency into sharp relief' (Nettleton, 2006).

Where Long Covid is concerned, the lack of clarity about the status of the condition itself is problematic for adults, but doubly so for children. Patients with Long Covid – especially children and adolescents (and their parents) – reported being negatively stereotyped in ways that diminish their credibility. In particular, they are viewed as being unreliable and untrustworthy knowers and testifiers of their own, or their child's, illness experience (Fricker, 2007) both because of the child's position in generational social ordering and their divergence from collective representations of the Covid-19 experience.

Common in accounts of people's experiences of medically-unexplained symptoms (Nettleton, 2006), participants in our study both rejected and considered psychological and physical explanations. This incongruity, exacerbated by Long Covid's lack of social currency, led to instances of Arthur Frank (1995) 'embodied paranoia', whereby participants feared or became wary of 'the institutions that [were] designed to help them.' In their aspirational quest for recognition in such an uncertain and unfriendly context, many parents worried about being accused of 'making up' or exaggerating their child's suffering and impairment. Our data demonstrate the additional work undertaken by children, adolescents and their parents in order to adequately signal the severity of their Long Covid illness as they navigated uncertain, 'medically unexplained' symptoms and an often unsympathetic public.

Though some symptoms may serve a signalling purpose to indicate when a person requires care and treatment (Shattuck et al., 2021; Steinkopf, 2015), this was not always possible with Long Covid due to the inconsistent and episodic nature of symptoms; the primacy of an official *diagnosis* (Jutel, 2009) was clear among participant accounts. Participants in our study frequently lamented the lack of clear biomarkers or definitive tests for Long Covid, demonstrating the strong value placed on being able to legitimise and 'permit' their illness experience through diagnostic tests. This lack of tests *alongside* often invisible, unusual or fluctuating symptoms – as is often the case with Long Covid (O'Brien et al., 2023) and other invisible conditions, like chronic pain – meant that the additional work of severity signalling needed to be done by participants, which was not always productive. Many reported difficulties in being able to sufficiently signal the severity of their illness to a largely unreceptive audience who still value visual cues of disability or illness (Lightman et al., 2009). This was exacerbated for children and adolescents with Long Covid, who contended with both a more limited capacity to articulate and advocate, and their status as 'unreliable candidates'. This additional work required of patients with Long Covid to elicit care, both in terms of sympathy and understanding from the public and appropriate medical attention, will be an important area to revisit in future research if and when diagnostic tests and treatments for Long Covid become available and as we learn more about the nature of Covid-19 and its long-term effects.

A key strength of this study is that, to the best of our knowledge, it is one of the first qualitative explorations of the experiences of children and adolescents with Long Covid. There are several study limitations related to narrating patient experiences. As with other conditions, we recognise that people with Long Covid are likely to have repeated their stories multiple times for peers and health professionals (Maclean et al., 2023). We acknowledge too that what patients take away from healthcare encounters may differ from the perspective or intent of the care provider. We also recognise that participants who took part in our study may not be representative of the wider population with Long Covid. For example, people who had no remittance from their symptoms may not have been able to take part in an interview, although we did talk to some people who had been severely unwell, for whom we accommodated with shorter interviews across different sessions. Finally, we acknowledge the highly temporal nature of these findings, and that the experiences of children and adolescents who have developed Long Covid more recently (2023 onwards) and their collective representations of the pandemic may well evolve.

5. Conclusion

Children and adolescents with Long Covid who were infected with Covid-19 early in the pandemic, and their parents, faced significant challenges in making their illness experiences visible and credible. Long Covid's lack of social currency at that time, coupled with participants' inability to engage effectively in 'severity signalling', alongside prevailing stereotypes about unwell children and their parents, contributed to children and adolescents' inability to gain traction with their peers, social circles and healthcare professionals. This has led to a 'double invisibility' of Long Covid in children. While this situation may change if/when definitive Long Covid diagnosis and treatment regimens become available, the issues described could apply to other conditions, including any characterised by pain and fatigue. The negative and deeply frustrating consequences for patients could be anticipated and ameliorated if this were more understood.

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CRediT authorship contribution statement

Cervantée Wild: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Alice MacLean:** Writing – review & editing, Formal analysis, Data curation. **Sarah Nettleton:** Writing – review & editing, Formal analysis, Data curation, Conceptualization. **Kate Hunt:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Sue Ziebland:** Writing – review & editing, Methodology, Investigation, Funding acquisition.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The authors do not have permission to share data.

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References

Alderson, P., 2007. Competent children? Minors' consent to health care treatment and research. Soc. Sci. Med. 65, 2272–2283.
Alderson, P., 2008. Young Children's Rights: Exploring Beliefs. Jessica Kingsley Publishers.
Alderson, P., Morrow, V., 2020. The Ethics of Research with Children and Young People: A Practical Handbook. Sage.
Au, L., Capotescu, C., Eyal, G., Finestone, G., 2022. Long covid and medical gaslighting: dismissal, delayed diagnosis, and deferred treatment. SSM-Qual. Res. Health 2, 100167.
Ballering, A.V., van Zon, S.K.R., olde Hartman, T.C., Rosmalen, J.G.M., 2022. Persistence of somatic symptoms after COVID-19 in The Netherlands: an observational cohort study. Lancet 400, 452–461.
Bourdieu, P., 1977. Outline of a Theory of Practice. Cambridge University Press, New York, NY.
Byrne, E.A., 2022. Understanding long covid: nosology, social attitudes and stigma. Brain Behav. Immun. 99, 17–24. https://doi.org/10.1016/j.bbi.2021.09.012.
Callard, F., Perego, E., 2021. How and why patients made Long Covid. Soc. Sci. Med. 268, 113426.
Cornwell, J., 1984. Hard-earned Lives: Accounts of Health and Illness from East London. Routledge.
Coyne, I.T., 1997. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? J. Adv. Nurs. 26, 623–630.
Davis, H.E., McCorkell, L., Vogel, J.M., Topol, E.J., 2023. Long COVID: major findings, mechanisms and recommendations. Nat. Rev. 21, 133–146.
Dumit, J., 2006. Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses. Soc. Sci. Med. 62, 577–590.
Durkheim, E., 1971. The Elementary Forms of the Religious Life, London, p. 9.
Dyson, S.M., Atkin, K., Culley, L.A., Dyson, S.E., Evans, H., 2011. Sickle cell, habitual dys-positions and fragile dispositions: young people with sickle cell at school. Sociol. Health Illness 33, 465–483.
Frank, A., 1995. The Wounded Storyteller, Body, Illness and Ethics. University of Chicago Press, Chicago.
Fricker, M., 2007. Epistemic Injustice: Power and the Ethics of Knowing. Oxford University Press.
Guell, C., 2007. Painful childhood: children living with juvenile arthritis. Qual. Health Res. 17, 884–892.

Hereth, B., Tubig, P., Sorrels, A., Muldoon, A., Hills, K., Evans, N.G., 2022. Long covid and disability: a brave new world. BMJ 378, e069868.

Herzlich, Claudine, Janine, Pierret, 1987. Illness and Self in Society.

Howell, J., 2022. COVID-19 narratives and layered temporality. Med. Humanit. 48, 211–220.

Ireson, J., Taylor, A., Richardson, E., Greenfield, B., Jones, G., 2022. Exploring invisibility and epistemic injustice in Long Covid-A citizen science qualitative analysis of patient stories from an online Covid community. Health Expect. 25 (4), 1753–1765. https://doi.org/10.1111/hex.13518.

Jaspal, R., Nerlich, B., 2023. Social representations of COVID-19 skeptics: denigration, demonization, and disenfranchisement. Polit. Groups, Ident. 11 (4), 750–770.

Jutel, A., 2009. Sociology of diagnosis: a preliminary review. Sociol. Health Illness 31, 278–299.

Jutel, A., 2010. Medically unexplained symptoms and the disease label. Soc. Theor. Health 8, 229–245.

Lightman, E., Vick, A., Herd, D., Mitchell, A., 2009. 'Not disabled enough': episodic disabilities and the ontario disability support program. Disabil. Stud. Q. 29, 1–26.

Loades, M.E., Crawley, E., Chalder, T., Flannery, H., 2021. Paediatric chronic fatigue syndrome: 25 year perspective. Clin. Child Psychol. Psychiatr. 26, 8–17.

Lobschat, L., Zinnbauer, M., Pallas, F., Joachimsthaler, E., 2013. Why social currency becomes a key driver of a firm's brand equity – insights from the automotive industry. Long Range Plan. 46 (1–2), 125–148. https://doi.org/10.1016/j.lrp.2012.11.004.

Maclean, A., Hunt, K., Brown, A., Evered, J.A., Dowrick, A., Fokkens, A., Grob, R., Law, S., Locock, L., Marcinow, M., Smith, L., Urbanowicz, A., Verheij, N., Wild, C., 2023. Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy. SSM. Qual. Res. Health 3, 100207. https://doi.org/10.1016/j.ssmqr.2022.100207.

Lopez-Leon, S., Wegman-Ostrosky, T., Ayuzo del Valle, N.C., Perelman, C., Sepulveda, R., Rebolledo, P.A., et al., 2022. Long-COVID in children and adolescents: a systematic review and meta-analyses. Sci. Rep. 12, 9950.

Mayall, B., 2002. Towards A Sociology for Childhood: Thinking from Children's Lives. Open University Press.

McFarland, S., Citrenbaum, S., Sherwood, O., van der Togt, V., Rossman, J.S., 2022. Long COVID in children. The Lancet Child & Adolescent Health 6, e1.

Nettleton, S., 2006. 'I just want permission to be ill': towards a sociology of medically unexplained symptoms. Soc. Sci. Med. 62, 1167–1178.

O'Brien, K.K., Brown, D.A., McDuff, K., Clair-Sullivan, N.S., Solomon, P., Carusone, S.C., et al., 2023. Conceptualising the episodic nature of disability among adults living with Long COVID: a qualitative study. BMJ Glob. Health 8, e011276.

Office for National Statistics, 2023. Prevalence of Ongoing Symptoms Following Coronavirus (COVID-19) Infection in the UK: 30 March 2023.

Roth, P.H., Gadebusch-Bondio, M., 2022. The contested meaning of "long COVID"–Patients, doctors, and the politics of subjective evidence. Soc. Sci. Med. 292, 114619.

Scambler, G., 2004. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. Soc. Theor. Health 2 (1), 29–46.

Shattuck, E.C., Perrotte, J.K., Daniels, C.L., Xu, X., Sunil, T.S., 2021. Signaling sickness: the role of recalled sickness behavior and psychosocial factors in shaping communication style. Evol. Med. Public Health 9, 221–231.

Smith, C., Odd, D., Harwood, R., et al., 2022. Deaths in children and young people in England after SARS-CoV-2 infection during the first pandemic year. Nat. Med. 28, 185–192. https://doi.org/10.1038/s41591-021-01578-1.

Sontag, S., 1978. Illness as Metaphor. Farrar, Straus and Giroux.

Steinkopf, L., 2015. The signaling theory of symptoms: an evolutionary explanation of the placebo effect. Evol. Psychol. 13, 1474704915600559.

UNICEF, 2023. Child-related policies in the first year of the COVID-19 pandemic in 40 countries [WWW Document]. UNICEF. https://www.unicef-irc.org/publications/1883-child-related-policies-in-the-first-year-of-the-covid-19-pandemic-in-40-countries.html. accessed 11.27.23.

Ziebland, S., Grob, R., Schlesinger, M., 2021. Polyphonic perspectives on health and care: Reflections from two decades of the DIPEx project. J. Health Services Res. Pol. 26, 133–140.

Ziebland, S., McPherson, A., 2006. Making sense of qualitative data analysis: An introduction with illustrations from DIPEx (Personal experiences of health and illness). Med. Educ. 40, 405–414.