


# Impact of COVID-19 on carers of children with tracheostomies

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## ABSTRACT

**Objectives** To explore the impact of the COVID-19 pandemic on the experiences of caregivers of children with tracheostomies.

**Design** Qualitative semistructured interviews.

**Setting** All participants were currently, or had previously cared for, a tracheostomised child who had attended a tertiary care centre in the North of England. Health professionals were purposively sampled to include accounts from a range of professions from primary, community, secondary and tertiary care.

**Participants** Carers of children with tracheostomies (n=34), including health professionals (n=17) and parents (n=17).

**Interventions** Interviews were undertaken between July 2020 and February 2021 by telephone or video link.

**Main outcome measure** Qualitative reflexive thematic analysis with QSR NVivo V.12.

**Results** The pandemic has presented an additional and, for some, substantial challenge when caring for tracheostomised children, but this was not always felt to be the most overriding concern. Interviews demonstrated rapid adaptation, normalisation and varying degrees of stoicism and citizenship around constantly changing pandemic-related requirements, rules and regulations. This paper focuses on four key themes: 'reconceptualising safe care and safe places'; 'disrupted support and isolation'; 'relationships, trust and communication'; and 'coping with uncertainty and shifting boundaries of responsibility'. These are described within the context of the impact on the child, the emotional and physical well-being of carers and the challenges to maintaining the values of family-centred care.

**Conclusions** As we move to the next phase of the pandemic, we need to understand the impact on vulnerable groups so that their needs can be prioritised.

## INTRODUCTION

Caregivers of children with tracheostomies must acquire skills in tracheostomy care, such as stoma care<sup>1</sup> to prevent potentially life-threatening complications.<sup>2</sup> Knowledge and confidence in delivering this type of care can be challenging to parents, carers and healthcare professionals alike.<sup>1,3-5</sup> The burden of care placed on carers has been associated with poor quality of life<sup>6-8</sup> and a negative impact on health status.<sup>9</sup>

At the start of the COVID-19 pandemic, there was an urgent need to optimise tracheostomy protocols to reduce the risk of SARS-CoV-2 transmission associated with aerosol-generating procedures.<sup>10</sup> In the UK, children with tracheostomies

## What is already known on this topic?

- ▶ Caring for children with tracheostomies in hospital, community healthcare settings and at home can be challenging.
- ▶ There was clinical uncertainty around the vulnerability of children with tracheostomies throughout the early stages of the COVID-19 pandemic, which resulted in rapidly evolving guidance.
- ▶ At the start of the COVID-19 pandemic, there was a need to optimise tracheostomy care protocols to reduce SARS-CoV-2 transmission associated with aerosol-generating procedures.

## What this study adds?

- ▶ Our findings describe how the COVID-19 pandemic has presented carers of children with tracheostomies with an additional and, for some, substantial challenge and increased burden.
- ▶ We highlight difficulties balancing general pandemic-related restrictions with the delivery of family-centred care and the need to provide consistent evidence-based guidance and support.
- ▶ Many of the issues identified in this study will have relevance to carers of children with other complex medical care needs.

were categorised as high risk and were advised to isolate at home until August 2020.<sup>11</sup> Despite rapid changes in knowledge,<sup>12-14</sup> there was clinical uncertainty around the vulnerability of children with tracheostomies throughout the early stages of the pandemic.<sup>11,15</sup> National tracheostomy safety project guidance was produced in August 2020<sup>16</sup> (updated January 2021)<sup>17</sup> in response to cautious pandemic-related approaches, such as the exclusion of children educational activities. Further guidance from the British Paediatric Respiratory Society was published in November 2020.<sup>18</sup>

This study set out to explore the experiences of caregivers of children with tracheostomies. The impact of COVID-19 emerged as a key theme during early data collection guiding our iterative approach to analysis and is the main focus of this paper.



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## METHODS

Qualitative semistructured interviews (n=34) were undertaken between July 2020 and February 2021 by telephone or video link with a maximal variation purposive sample of health professionals and parents of children with tracheostomies who had attended a tertiary care referral centre in the North East of England.

Health professionals were purposively sampled to include variation of accounts in relation to professional roles and healthcare settings, including different levels of experience of providing care for children with tracheostomies. Parents were sampled to include accounts from those with children tracheostomised prior to and during the pandemic and from across the geographical region. Topic guides were developed initially based on key areas from the extant literature and allowed participant-led discussion. Concurrent data collection and analysis allowed refinement of the topic guide based on initial interviews and continued until no new themes were evident with the data (data saturation). Recruitment of further participants ceased on data saturation and therefore this informed our sample size in both groups. Informed consent was obtained. All interviews were recorded and transcribed verbatim. Transcripts were anonymised and coded with the help of NVivo QSR International Pty Ltd software V.12, 2018. Exploratory data analysis was conducted iteratively in line with Braun and Clark's six phase approach to reflexive thematic analysis<sup>19</sup> with a focus on the pandemic-related themes. Interviews and analysis were conducted by an experienced qualitative researcher (NH).

## RESULTS

Interviews were completed with 17 parents (15 families) and 17 health professionals and lasted 40–125 min. Participant characteristics are summarised in table 1. Most parents had children with additional complex needs. Two children and their families had tested positive for COVID-19 prior to interview. None were described as having suffered from serious illness as a result.

We describe four key themes relating to carers' experiences of providing tracheostomy care during the pandemic. These interconnected themes are described within the context of the impact on the child, the emotional and physical well-being of carers and the challenges posed in relation to maintaining the values of family-centred care.

## Reconceptualising safe places and safe care

Participants' accounts illustrated how the pandemic had required consideration of safety in relation to care environments and the 'new normal' of caregiving specific to COVID-19 transmission and infection risk within the context of tracheostomy care. This influenced how they had adapted to create, normalise and maintain safe environments and care for tracheostomised children in light of evolving knowledge, understanding and guidance. Table 2 provides examples of some key barriers, facilitators and impact associated with this process.

In line with guidelines, ensuring safety involved significant changes such as shielding, the provision of virtual appointments, personal protective equipment (PPE), processes to ensure 'safe routes into hospital' and visitor restrictions. Due to the nature of the COVID-19 threat, and despite recognised challenges, carers generally reported having accepted and quickly adjusted to the changes.

[I]t was a lot of the unknown and anxieties from our part, because you didn't know what you were... really what you were contending with. Then now it feels like the new normal. (HP14)

**Table 1** Participant characteristics: families and health professionals

	Numbers	Identifiers
<b>Parents (n=17)</b>		
<b>Time since tracheostomy at interview</b>		
<1 year	6	P1, P3, P8, P14, P13, P17
>1–5 years	6	P2, P4, P5, P7, P10, P11
>5 years	5	P9, P16, P19, P20, P21
<b>Hospital admission or visit during pandemic</b>		
Tracheostomy during pandemic	5	P1, P8, P13, P14, P17
Other hospital admission/ in-person appointment during pandemic	7	P4, P5, P11, P10, P16, P19, P20, P21
No hospital contact during pandemic	5	P2, P3, P7, P9, P14
<b>Carer interviewed</b>		
Mother	14	P1, P2, P3, P4, P5, P7, P8, P9, P14, P17, P16, P10, P19, P21
Father	3	P11, P13, P20
<b>Health professionals participant (n=17)</b>		
Specialty		
Otorhinolaryngology: surgeons and specialist nurse	3	HP1, HP7, HP11
Paediatrics: respiratory paediatrician, respiratory nurses, occupational therapists, speech and language therapists, emergency department nurses, intensive care nurses, general paediatrician and specialist transport services staff	11	HP2, HP4, HP5, HP6, HP8, HP9, HP10, HP12, HP13, HP14, HP17
Community/primary care: community nurses and general practitioner (family doctor)	3	HP3, HP15, HP16

Nevertheless, accounts demonstrated that adherence to generic rules intended to reduce risk of COVID-19 infection and transmission could also conflict with the principles of 'family-centred care', prioritising the complex and individual needs of children and families. This seems to have created a challenging balance for health professionals and parents that fluctuated over the course of the pandemic. Visitor restrictions in hospitals, for example, were reported to have had significant impact on carers and their families.

Although parents recognised that responsibility for maintaining safe healthcare environments was mainly under the control of the health professionals, they felt ultimate responsibility for keeping their child 'safe' more generally across all settings. Particularly for those who had spent a long time in hospital during the pandemic, this resulted in frustration and anger in response to unclear rules and procedures often inconsistently applied across hospital wards and by different staff. For some parents, safety concerns had resulted in hesitancy to seek care for non-life-threatening situations and taking on increasing responsibility for their child's medical needs. This was reported to be context specific, depended on the level of concern and changed over the course of the pandemic

I don't care what it is, unless it's an emergency, we're not coming back (to hospital). (P8)

[A] lot of parents were scared, ... some parents didn't really want to come to hospital, didn't want anybody from the hospital coming out to them either... because they were concerned you know catching Covid...'. (HP7)

**Table 2** Reconceptualising safe care and spaces and adapting to the new 'normal'

	Influences on reconceptualisation of safe care and adapting to 'the new normal'		Carers' views on challenges to adapting to COVID-19 related changes in care	Carers' experiences of impact of COVID-19 pandemic and associated restrictions	
	Barriers	Facilitators	Challenges	Positive impact	Negative impact
<b>Examples</b>	<ul style="list-style-type: none"> <li>▶ Uncertainty.</li> <li>▶ Changing knowledge, information rules, guidance and regulations.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Normalisation of personal protective equipment (PPE).</li> <li>▶ Availability and access to technology.</li> <li>▶ Local leadership, team working and problem solving.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Need to enforce rules and policies that can at times contradict usual principles of family-centred care.</li> <li>▶ Uncertain sustainability of new ways of working.</li> <li>▶ Complexity of care needs and range of health professionals involved in the care of children with tracheostomies.</li> <li>▶ Ensuring flexibility to account for individual needs of carers as well as children, such as hearing impairments, communication difficulties, etc.</li> <li>▶ Need for complex decision making around risk with fluctuating knowledge and guidance.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Improved interdisciplinary working in some areas.</li> <li>▶ Reduced infection risk for children at high risk.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Delayed healthcare seeking.</li> <li>▶ Parental emotional support sources disrupted.</li> <li>▶ Mental health impact on families and parents isolated on hospital wards and at home.</li> <li>▶ Restricted or removed access to support and care from school/family/respite care.</li> <li>▶ Increased burden and pressure on staff.</li> <li>▶ Usual routines and equipment provision disrupted.</li> <li>▶ Negative impact on communication, trust and relationships with parents/staff.</li> <li>▶ Other practical and financial impact: for example, socioeconomic and employment issues; unable to register birth with impact on legal parental responsibility during times of difficult decision making around the care of the child.</li> </ul>

For those with established tracheostomies, reliance on support and social and respite care posed an additional challenge to providing a 'safe' care environment at home. This involved complex assessment of risk, based on confusing and fluctuating information and had exacerbated the emotional burden of caring for a child with a life-threatening condition.

You didn't know where you wanted to be for the best really... It was safer for [child's name] at home... and obviously at that time, you don't want them [community nurses/respite carers] in your house but you have to... (P3).

[O]ur concern at the moment isn't so much about [sibling] and [child] getting it... our biggest concern is if [husband] and I catch it, and we're in a position where if we're too poorly to care for the children. We have no contingency, at all. (P19)

Despite describing many negative consequences of the pandemic, increased community awareness of infection risk and other social contact restrictions had also allowed some parents to feel more control over keeping their home environments safer for children already at high risk of other respiratory infections

[I]t's been a treat... he hasn't had a chest infection since the very beginning of this year, whereas, I think by now we would have had a lot more. (P11)

[P]eople are so much more aware now, there's so much more hand washing, there's so much more masks... Covid, for a respiratory baby, who needs to get through the next few years and grow some lungs... probably not the worst thing that could have happened to him. (P13)

### Disrupted support and isolation

Some of the most significant issues highlighted in relation to the efforts to minimise COVID-19 infection risk and maintain safe spaces were the disrupted support caused by shielding, isolation of parents caused by shielding, visitor restrictions in hospitals and challenges associated with respite care. This affected participants in different ways. [Table 3](#) provides illustrative quotes relating the difficulties and impact on mental health and well-being associated with

exacerbation of isolation and lack of social support due to the pandemic.

Hospital visitor restrictions and limited access to usual support from partners and extended family was a particular challenge for those whose children were tracheostomised during the pandemic, as well as those with existing tracheostomies who had spent extended periods of time isolated on hospital wards. When asked about what had been the most difficult aspect of her experience, one mother responded: *'Having to be away from the family (sibling and husband) with my daughter in the hospital'* (P14). Nursing staff reported how there had been an increased need to provide emotional support to parents trying to cope on their own with having a seriously ill child.

(it's) hard for all families but those with traches need extra support and help. (HP13)

Isolation and disruption to usual support was also an issue for those with children with established tracheostomies at home. Access to suitable respite care and support was described as an ongoing difficulty generally, particularly in relation to funding and availability of experienced home carers. However pandemic-related restrictions were reported to have further disrupted access to formal (including school-based and health or social care funded support) and informal (extended family and friends) respite care. This was reported to have placed increasing burden on parents to provide 24-hour care with little or no access to support.

Parents described different ways that the need to try to minimise transmission risk to their child and families had impacted on their living arrangements. This evolved throughout the course of the pandemic, but examples included parents living apart for extended periods, so that one parent could continue working, moving in with extended family to access support or restricted contact within the household.

For many of the families, schools provided essential respite care, specialist support such as intensive physiotherapy and met the stimulation and development needs of those children with

**Table 3** Difficulties and impact on mental health and well-being associated with exacerbation of isolation and lack of social support: illustrative quotes

Subthemes	Illustrative quotes
Emotional impact of isolation in hospital Disrupted support	'[E]ven though they'd told us he was potentially gonna die, we still weren't allowed in together to see him... It- it was hard'. (P1)  '[I]nitially, erm, it didn't look very good, it didn't look like she was going to pull through... and to be the only parent who's there and facing the, that your child dying... I didn't know what to do'. (P8)  'I think obviously, at the minute (due to pandemic), you don't have the support around you of the people that you know ... it therefore causes overreactions or upset just because it's... you're not thinking as straight as you were if you had somebody else around you to keep your mind sensible... I think mentally, I think it does, I think it, it takes its toll, being separated'. (P13)  'I think he's received all of the appropriate medical treatment he should have had..., everything was, kind of, full steam ahead. There was no delays with anything. It's more the emotional side, so being on my own when he had his tracheostomy. I was the only one allowed in the PICU* that day to see him. So his dad couldn't see him and then we weren't allowed to be in the same room together. Erm, so we had to swap off the hospital site, which is a bit ridiculous considering anybody can walk in off the street and get a Costa from the hospital, they're the rules. Erm, we weren't allowed to be together'. (P17) *Paediatric intensive care unit
Emotional impact of isolation in hospital Anxiety about risk	'And obviously I wasn't allowed no visitors at (hospital), so... I was just on me own for the full eight weeks up there... I think I've just felt like I've been in the worst position because of it's been in the middle of a pandemic, hasn't it?... I don't think I'd be as anxious and as bad as I have been if there wasn't all this COVID going on and what-have-you'. (P14)
Emotional impact of isolation in hospital Disrupted families	'But it's just really hard when you're in hospital for that long and you don't spend any time as a family. We've got a little girl..., so she was only two when all this was going on... So, you're, you're stuck in that room. It's really hard. It's lonely. You spend no time together as a family. It's just, it's hard on everyone'. (P17)  'having gone through everything with (child name) as a pair or as a three (with sibling) and being told you're only allowed one adult is very difficult'. (P4)
Emotional and well-being impact Shielding	'Before lockdown it was hard for me to do anything... So like at least going into work was like a little bit of an escape so it was a little bit of time away... where I am being me and not just mam and sort of trache nurse sort of speak... that's something that I haven't had, so because I put the kids to bed on a lunchtime, that's me upstairs in the room, where (child's name) is... so I don't get any time away'. (P2)  '[I]t (isolation and lack of respite care) was torture, because she had to shield'. (P16)
Emotional and well-being impact Disrupted access to usual support mechanisms and respite care	'A few times she was back at school that I had a bit of time to myself, but other than that it's just been really intense... I need, I need to look after myself and take better care of myself because I can be all this brilliant mam and be there for my kids but if I run meself ragged, do you know what I mean I'm gonna take that away from them aren't I... So important that I take some time for meself so, that's why hopefully it's important to get (child name) back to school'. (P5)

additional complex learning needs. Due to initial uncertainty about the transmission risk associated with tracheostomies, access to schools was inconsistent and was still proving to be problematic for many of the families.

Lack of access to support and respite care and isolation due to shielding and lockdown restrictions placed increasing pressures on parents' own physical and mental health and well-being, and for those in employment, posed additional challenges around work and financial concerns.

[M]entally that was quite difficult for him that monotony... educationally lost out on quite a bit as well. (P9)

'[S]o it's been pretty tough because we both work, me and his dad work, I've had to take unpaid leave and his dad was furloughed due to the COVID-19'. (P3)

The impact of the pandemic on isolation and disruption to everyday life, however, was not always easy to distinguish from 'normal' challenges associated with caring for a tracheostomised child, particularly for those whose child had been tracheostomised during the pandemic or those who already felt isolated.

### Relationships, trust and communication

Although there was a high level of acceptance around pandemic-related uncertainty and changes, the pandemic seemed to accentuate issues around power, rapport and trust, particularly if these were already strained. Some parents who had spent long periods of time on different hospital wards during the pandemic reported being frustrated by the lack of consistency in interpretation and delivery of the rules and regulations. This impacted

on trust and in one case had resulted in a significant breakdown in communication and conflict.

Although most parents were positive about the support they received from healthcare teams, the isolation felt by parents was in contrast to the importance placed on team working and support from colleagues reported by health professionals.

[W]e're getting through it as a team whilst still wanting to deliver, you know, high standards of care to the families we're looking after. (HP12)

Children with tracheostomies have large multidisciplinary teams to support their care needs. Adaptation had relied on team working, local leadership and problem-solving skills of teams and individuals. An increased reliance on video-conferencing was generally perceived to have had a positive impact on interdisciplinary team working. Technology enabled virtual clinics were reported to offer important advantages for children and parents, particularly those who find the burden of travelling with their child to appointments difficult. However, the sustainability of this approach for families, whose children need to be seen face to face regularly for medical assessment, was questioned, as it could also make parents feel abandoned, threatening trust and valuable relationship building.

It's gonna be really good for moving on in the future when things kind of go back to whatever the new normal will be. (HP6)

[I]f it remains remote, ... the thread between them is, is pulled and potentially can weaken and then there's not as much trust and people are more likely to feel abandoned. (HP15)

**Table 4** Perceived impact of personal protective equipment on children: relationships, communication and development

Relationships/rapport	Development
'[F]or a new child having identity and a face to a voice is important in maintaining and developing caring relationships'. (HP13)	'Face masks and, you know again if they've got associated, you know, problems with development it's, you know, they just, they can't understand what you're saying, erm, you know, when you've got masks on and, you know, just all those general communications. But yeah, we look a bit more frightening when we've got masks on and visors, and long-sleeved aprons and, and things like that'. (HP3)
'[N]ow the little girl can't really see our faces underneath the face mask and visor so she's probably a lot more scared from that point of view that has been difficult' 'usually they know faces what we look like, whereas now that aspect has been taken away a bit... It's been difficult to build relationships with them through a mask and visor'. (HP6)	[n]ow we're all wearing masks, we're not even seeing our mouth movements for you know copying those... I think that the frustrating side is that they can't see your mouth and I do find that quite weird sometimes um if you're trying to kind of encourage talking or eating um it does look a bit strange, so that's been frustrating. I know that there are clear masks available... I think they still come with their problems, but, um, you know that might be something to think about going forward'. (HP4)
'I think it will have issues down the line... you can be smiling and cooing and trying to interact with the baby and if all they can see in your eyes it's quite difficult'. (HP6)	
'It was in the middle of the whole COVID crisis and everybody was, erm, wrapped up, masks and visors, goggles, the whole kit and caboodle and her vision is, she's visually almost blind in one eye and only has poor vision in the other eye, so she relies very much on being able to see your face... what you look like as to where her range of emotions should be as well... I think the fact that all of these people who were wearing, you know, really quite scary stuff when you're not very, very well and, you know, be coming in, there was lots, I mean she was hooked up to, God knows, everything and people are suctioning and bashing your back and putting ice packs in and, so her memory of that is these people tend to do not very nice things to you... So, I think it's, I think for, for kids it's just been really, really difficult'. (P8)	
'I can't hear properly, you smile anyway you stay busy, you're trying to make a funny face to get a bit of a response and I'm still doing that in a mask, knowing that they can't see me'. (HP13)	
'[S]at at the kitchen table in a mask and they are in their high chair and they look at you a bit funny, but it's actually been ok'. (HP4)	

The need to wear PPE, in particular face coverings, was also reported to have had an impact on building and developing relationships with the child and family. In the main, most participants reported that they and the children they cared for had adapted quickly to the use of face masks. The inability of children with additional communication needs to see or recognise faces also presented a challenge for rapport and communication (see table 4).

Health professionals described a number of adjustments that had been made either at team level, such as including stickers on visors to make staff appear more friendly and recognisable, or at an individual level, taking considered risks and adjusting rules and requirements to ensure rapport building.

### Coping with uncertainty and shifting boundaries of responsibility

Coping with pandemic-related uncertainties presented an additional, and for some substantial, difficulty for parents on top of existing challenges associated with providing 24-hour care for their child and dealing with complex medical equipment and life-threatening situations. The pandemic was, however, not always seen to be the biggest challenge they faced, in light of the life-changing experiences and responsibilities associated with having a child with a life-threatening condition. Accounts illustrated high levels of required resilience associated with adapting to the impact the pandemic was having on their own 'new normal' and already disrupted lives.

[I]t's difficult having a child with a life-threatening medical condition... it's hard at the best of times but (pandemic has) made it even more complicated than it probably would have been. (P5)

COVID wasn't, isn't the biggest issue happening in [child's] life at the minute. (P8)

So, it hasn't massively changed a lot for me because... Before lockdown it was hard for me to do anything. (P2)

Uncertainty in relation to the pandemic seemed, however, to have been normalised and accepted due to the unusual context. Parents' narratives were commonly positive and stoic even when describing significant pandemic-associated challenges and impacts on mental health and well-being.

Its (living with Covid) a bit like having a kid with a trache isn't it? You've just got to deal with it. You've got to put measures in place, do the best you can to keep you and your family safe and, that's all you can do. (P5)

Health professionals' accounts also displayed rapid normalisation and a degree of stoicism around acceptance and adaptation to changes despite a high level of uncertainty around variable and changing guidance and information. They described a need to balance abiding by new rules and guidance with their own safety and the safety of the child and well-being of the family. This was particularly apparent in light of uncertainty around risks and professional duties of care in life-threatening situations.

[T]o me, she (nurse) did the right thing for my boy, but she didn't do the right thing for COVID, and she didn't do the right thing for A&E, and she didn't do the right thing for herself. (P1)

Adaptations to accommodate the needs of families could also place additional burden on staff time and resources with increased need for nurses to support the emotional and mental health needs of parents isolated on hospital wards. Other staff described involvement of health professionals in ensuring children were able to attend school. The need for restrictions, changes in processes and fluctuating information was nevertheless reported to have caused frustration confusion and additional anxiety.

There seemed to be an assumption and burden of responsibility placed on parents to 'know' how to keep their child safe, despite a lack of clarity around how best to do so. Narratives

from health professionals at times highlighted expectations that parents knew what was 'safe' and when clinical assessment was required, extending further the care duties and responsibilities placed on parents pre-pandemic.

[T]he parents are very sensible, and they don't want to put children at risk, so they'll have been shielding at home. (HP5)

[P]arents would have highlighted any concerns. (HP10)

Reported confidence of the parents was more varied. One parent described how they felt responsible for decisions around help-seeking that might have put their child at risk.

I just keep getting told to go to hospital, but I mean can you imagine how stupid I feel rocking up at A&E when it's COVID if it isn't actually anything wrong with him... I'm increasing me risks of catching COVID, never mind [child's name] me and his dad coming to A&E. (P1)

It was acknowledged that although the pandemic had affected everyone, there had been an increased burden of responsibility placed on parents of children with tracheostomies and other complex care needs. Some parents also described an increased burden of responsibility for their child's needs and well-being due to the uncertainty and disruption to their usual support mechanisms and respite care arrangements.

[A]t the moment, we're kind of living on a fingers crossed, nothing's really wrong with him. (P9)

[I]t's difficult anyway, COVID is making it harder... (P5)

## DISCUSSION

Our findings describe how pandemic-related reconceptualisation of safe spaces and care practices have exacerbated existing isolation and challenges for many parents and carers. Frustration around inconsistent pandemic-related guidance seems to have placed pressure on trust, communication and relationships, which has been, for some, compounded by PPE requirements. The loss of support and access to respite care for parents were found to have been contextualised in relation to difficulties and uncertainties, resilience and stoicism. There were, however, unanticipated benefits of increased community awareness of respiratory infection risks. We highlight difficulties balancing general pandemic-related restrictions with the delivery of family-centred care. Many of these issues will have relevance to families with children with other complex medical care needs.

A potential limitation of our findings is that parent participation was focused on the experiences of carers of children from one tertiary care centre. Furthermore, we had a limited number of fathers (3/17), so the family responses were biased towards the mothers' perspectives. Only two participants reported that their child and families had tested positive for COVID-19. Potential for comparisons based on these characteristics and experiences was therefore limited. In addition, we had no responses from other formal and informal carers (eg, grandparents, social carers and siblings) and children were not included. We would advocate for the inclusion of a more diverse pool of participants in future studies. Many of the parents described the impact on their employment and financial situations and how the pandemic had exacerbated existing difficulties, mainly due to restricted access to respite care and working parents being furloughed. Our analysis did not specifically compare experiences based on sociodemographic or employment characteristics of parents however, and this may be another area for future research.

Caring for children with medical needs requiring multiple medical procedures and equipment places a significant burden on families.<sup>20-22</sup> Disease burden has been shown to be higher for

children and families with tracheostomies than for other serious childhood diseases and is associated with lower quality of life for carers.<sup>6 7 23</sup> Our findings describe how the pandemic has presented carers with a substantial additional challenge. Nevertheless, in line with existing qualitative evidence describing how the lives of these families can be 'highly complicated and frequently overwhelming'<sup>24</sup> and the associated psychological burden and daily struggle,<sup>8 9</sup> the pandemic was not always seen to be the most significant challenge they faced. The difficulties associated with knowledge and confidence in delivering tracheostomy care,<sup>1 5 25-27</sup> adapting to the transition from hospital to home and coping with the responsibilities of medical care, disrupted lives<sup>3 28</sup> and dealing with care coordination<sup>9</sup> has also been highlighted by others. Narratives from parents and health professionals demonstrated rapid adaptation, normalisation and varying degrees of stoicism and citizenship around constantly changing pandemic-related requirements. These reflect and extend themes of resilience and enrichment in previous qualitative work with carers of children with tracheostomies and other complex medical needs.<sup>23 24</sup>

As we move to the next phase of the pandemic, we need to understand the impact on vulnerable groups so that their needs can be prioritised. Levels of anxiety around COVID-19 transmission risk were already starting to reduce nationally near the end of our data collection period. It is possible that as the national vaccination programme, restrictions and shielding advice has evolved, integration within educational settings, access to respite care and other healthcare related challenges may have improved for this group of children and their families. Nevertheless, despite ongoing debate and high levels of COVID-19 in school settings, vaccines are not routinely available for under 12 years in the UK,<sup>29</sup> and there may still be concerns and challenges associated with the risks for vulnerable children in this setting. Staff shortages across social care more widely are likely to also be compounding existing issues in relation to access to appropriate respite care and support. The impact of the pandemic on access to hospice-based and social services funded respite centres were not highlighted in the accounts of our participants but may be of relevance to other families.

The importance of consistent evidence-based guidance, support and interprofessional working across health, social care and education settings has been demonstrated as crucial to helping families and health professionals. Groups such as the British Paediatric Respiratory Society and National Tracheostomy Safety Project have built a body of resources to help provide more consistency. These can form the basis of education and training for staff, parents and other carers in the future.

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