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Providing care for children with tracheostomies: a qualitative interview study with parents and health professionals

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Abstract

Objectives: To explore the experience of caring for children with tracheostomies from the perspectives of parents and health professional caregivers.

Design: Qualitative semi-structured interview study

Setting: One region in England covered by a tertiary care centre that includes urban and remote rural areas and has a high level of deprivation.

Participants: A purposive sample of health professionals and parents who care for children who have, or have had, tracheostomies and who received care at the tertiary care centre.

Results: This paper outlines key determinants and mediators of the experiences of caregiving and the impact on psychological and physical health and quality of life of parents and their families, confidence of healthcare providers, and perceived quality of care. For parents, access to care packages and respite care at home as well as communication and relationships with health care providers are key mediators of their experience of caregiving, whereas for health professionals, an essential influence is multi-disciplinary team working and support. We also highlight a range of challenges focused on the shared care space, including: a lack of standardisation in access to different support teams, care packages and respite care; irregular training and updates, and differences in health provider expertise and experiences across departments and shift patterns, exacerbated in some settings by limited contact with children with tracheostomies.

Conclusions: Understanding the experiences of caregiving can help inform measures to support caregivers and improve quality standards. Our findings suggest there is a need to facilitate further standardisation of care and support available for parent caregivers and that this may be transferable to other regions. Potential solutions to be explored could include the development of a paediatric tracheostomy service specification, increasing use of paediatric tracheostomy specialist nurse roles, and addressing the emotional and psychological support needs of caregivers.

Strengths and limitations of this study

- By including perspectives of parents and health care professionals who care for children with tracheostomies, our analysis allowed for novel and valuable comparisons to be made around the shared care space.

- The inclusion of accounts from health care professionals from primary, community, secondary and tertiary care allowed rich insight into carer experiences across organisational boundaries.
- Our study took place across one large geographic region in England that covers rural and urban areas and has higher levels of deprivation than the rest of England, however transferability to other settings may be dependent on local service structures.
- We were not able to include perspectives of carers providing respite care and support based in social care and educational settings.
- Despite participant accounts covering experiences from earlier time points, data collection took placed during the Covid-19 pandemic which had an impact on the experiences of care and caregiving.

BACKGROUND

Tracheostomies are performed in children mainly to facilitate long-term ventilation, in cases of airway obstruction or neurological impairment.[1-3] Only a quarter to half of children who rely on a tracheostomy are decannulated, and for those who are, the average time before decannulation is two years. [4 5]

Tracheostomies can be associated with potentially fatal risks such as airway obstruction, mucus plugging, tube displacement, bleeding and infection. [6 7] Parents, health care providers (HCPs) and other carers must undergo a comprehensive training programme and competency assessments in order to manage required aspects of care, including providing suction, stoma care, tube changes and resuscitation. [8 9] Training, knowledge and confidence in delivering this type of care, can remain a challenge for parents and health care providers alike. [10 11 12-14]

The burden of care on families caring for children with complex medical needs has been reported to be greater than understood by HCPs or the general public, prompting calls for better preparation and support for families. [15] Quality of life of parents and carers of children requiring tracheostomy, who can also have a range of other complex health care needs, is poor and has been reported to be worse than those with children with other chronic conditions, such as diabetes, cancer and renal disease. [16] Caring for a child with a tracheostomy has been shown to significantly affect carers sleep, emotional wellbeing, relationships and family life. [7 10 17]

A literature review in 2013 highlighted the lack of qualitative research investigating caregivers' views and experiences of looking after a child with a tracheostomy. [7] Since this review, there have been a limited number of studies completed within the UK setting, although these have made a valuable addition to our understanding of the burden of care on these families and their training needs. [8 9] Qualitative research from other countries has also focused on specific experiences, such as decision-making around tracheostomy procedures and risk communication, [12 18 19] transition to home, [20-23] and the perspectives of children and young people themselves. [24] Transferability of these findings to the UK healthcare setting may be limited. These studies have mainly focused on the experiences of parents or other informal carers. [25] There has been limited research that includes the perspectives of professional HCPs.

We therefore sought to explore the experiences of both parents and health care provider caregivers, to allow valuable comparisons with a focus on the interface with the health and care system across health care and home settings. Through this exploration we aimed to provide insights into care quality improvements and, or measures to improve the experience of caring, and quality of life, for carers.

METHODS

Qualitative semi-structured 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 of England. This centre serves a region that includes urban and remote rural areas and has an above average level of deprivation compared to the rest of England.[26]

Participants and sampling

All potential participants were approached by a clinician from a tertiary care centre with expertise in paediatric tracheostomy and provided information about the study in person, by email, or post. Health professionals were purposively sampled to include variation of accounts in relation to professional roles (nurses, doctors, allied health professionals) and healthcare setting (covering primary, community, secondary and tertiary care) from across the North East of England and with different levels of experience of providing care for children with tracheostomies. Parents with experiences of caring for a child with a tracheostomy were purposively sampled to include diverse accounts in relation to age of child, range of additional care needs, time since the procedure, and from those living across the large geographical region covered by the same tertiary care centre.

Data collection and analysis

Topic guides were developed based on key areas from the extant literature, whilst allowing opportunity for participant-led discussion. Data collection and analysis continued iteratively and concurrently and continued until no new themes were evident within the data (data saturation). All interviews were recorded and transcribed verbatim and field notes were recorded after each interview. Transcripts were anonymised and coded with the help of NVivo QSR International Pty Ltd software version 12, 2018.

Exploratory data analysis was conducted iteratively in line with Braun and Clark's six phase approach to reflexive thematic analysis [27]. This involved: familiarisation with the data, initial coding, generating "patterns of shared meaning" (themes), reviewing and validating themes, defining and naming themes, interpreting and reporting. The coding process was informed, but not restricted, by qualitative evidence on experiences of care providers of children with complex medical needs [28] and key constructs from a theoretical model of the experiences of caregiving, the Informal Caregiving Integrative Model (ICIM). [29] The ICIM was developed based on integration of evidence from work around informal caregiving stress and professional burnout. The processes

described within this model were felt to be applicable to understanding the experience and impact of providing care more widely, despite stress and burnout not being a specific focus of our study. This informed our initial coding and theme development; however, the main emphasis of our analysis was placed on inductive coding to allow prominence to the voices of our participants. Initial coding was developed into key themes that described the determinants and mediators of the experience of caregiving in this particular context, as well as the impact this had on families, healthcare providers and children. The themes described in this paper focus on the influences on the experiences of caregiving at the interface with the health and care system from the perspectives of healthcare providers and parent caregivers. Other significant and crucial aspects of parents' experiences of caregiving, such as the consequences on identities, employment and financial security, biographical disruption, and parenting roles, are not covered in-depth here. Furthermore, data collection took place during the early stages of the Covid-19 pandemic, which had a substantial impact on the experiences of caregiving at the time of the interviews. This was an important contextual factor that was accounted for during the interpretation of our findings but is described in more detail elsewhere.[30] Interviews and analysis were conducted by an experienced postdoctoral qualitative researcher (NH) positioned outside of both the health and social care provision and work context of participants.

Patient and Public Involvement

Carers of children with tracheostomies were consulted about the project, but were not specifically involved in the design, conduct, reporting or dissemination of the work.

RESULTS

Interviews (n=34) were completed with 17 parents (15 families) and 17 professional health care providers (HCPs). Participant characteristics are summarised in tables 1 and 2. Most parents had children who had a range of complex needs in addition to their tracheostomy and one had recently been decannulated.

Table 1 – Participant characteristics: Parents (n=17)

	Numbers	Identifiers (Parent)
Time since tracheostomy at interview		
<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
Child's age at tracheostomy		
<1-6 months	11	P2, P4, P7, P9, P10, P11, P14, P16, P17, P19, P20,
7-12 months	3	P1, P13, P21
>1 years	3	P3, P5, P8
Carer interviewed		
Mother	14	P1, P2, P3, P4, P5, P7, P8, P9, P14, P17, P16, P10, P19, P21
Father	3	P11, P13, P20

Table 2 – Participant Characteristics: Health care providers (n=17)

Speciality	Role	Numbers	Identifiers (Health care provider)
Otorhinolaryngology	Surgeons and specialist nurse	3	HCP1, HCP11, HCP7
Paediatrics	Surgeon/Respiratory clinicians/nurses	4	HCP8, HCP9, HCP10, HCP6
	Allied health professionals, A&E/Intensive care nurses	5	HCP4, HCP12, HCP13, HCP14, HCP17
Community /primary care	Community nurses	2	HCP3, HCP16
	GP	1	HCP15
Other	Secondary care paediatrician	1	HCP2
	Specialist transport services staff	1	HCP5

Interviews (n=34) lasted from 40 to 125 minutes. Accounts from HCPs and parents differed in relation to content and depth of narratives with most HCPs' interviews being shorter. This reflected both the more limited experiences of caring for children with tracheostomies by some of the HCPs interviewed, but also that caregiving was experienced and described as part of their professional roles. For parents, on the other hand, experiences of caregiving were inextricably intertwined with their everyday lives and identities as parents. This involved the sharing of more personal accounts and additional thematic complexity.

We describe below key themes identified within the interviews and evidence our findings with verbatim participant quotes qualified with anonymous identifiers. Figure 1 provides a summary of the key determinants and mediators associated with different aspects of the caregiving experience reported by the participants in our study which will be described in more depth here. This figure also illustrates our coding framework.

Insert figure 1 – Influences on the experiences of caregiving

Individual "back stories"

Our theme of individual "back stories" came from the words of one of our participants who used this term to refer to important aspects of their lived context and experience that impacted on their caregiving. This theme also maps to the caregiver demands and resources element of the ICIM model.[29]

As to be expected, key aspects of the "back stories" reported by participants that influenced the experience of caregiving differed between parent caregivers and HCPs. These determinants impacted on various aspects of their caregiving experience, including: perceived ability, capacity and confidence in being able to provide high quality care, perceived and actual burden of care, beliefs about the caregiving role, as well as interactions with and within the healthcare setting.

Parent caregivers

For parents, ability and capacity to deal with the demands and burden of caregiving included: their own existing physical and emotional health; family background and circumstances; complexity of their child's care needs; and previous experiences within the health care setting. The following quote illustrates the processes in figure 1 from the perspective of one single parent who described how key

aspects of her own "backstory" had shaped her experiences of caregiving and her perceived ability to deal with the learning requirements associated with providing tracheostomy care for her child. It also highlights how interactions within the health care setting were integral to this experience. In this example, she recalls how one interaction had exacerbated the burden of adapting to the demands associated with becoming the sole caregiver of a child requiring 24 hour care, whilst dealing with the associated biographical disruption to her own life.

> *"Some of them listened to your back story ... I probably am a bit slower than other people, do you know? there's no shame in that like but, some of them I just think were just like, a bit rude to me. …I want to add I'm at me discharge meeting at me lowest ever ebb, and I'm so down [emotionally] and I just remember thinking you just don't get it do you? You just really don't get it like, this is what I'm gonna have to go home to, this is gonna be twenty-four seven to me. The carers they don't get it neither because they clock off and go home." (Parent 5)*

HCP caregivers

For HCPs whose narratives were primarily grounded within their professional rather than personal experiences, their "back stories" were mainly related to: HCP role and work setting; professional competence and confidence; level and frequency of caring for patients with tracheostomies; and knowledge and training in tracheostomy care. Depending on their professional role and work setting, commonly mentioned challenges included limited opportunities to gain experience of caring for tracheostomised children due to limited frequency of contact, as well as the importance of access to training and updates. One of the HCPs described how the learning from an initial training day was difficult to embed due to infrequent exposure, which was more of an issue for those not working within specialist tertiary care paediatric wards where dealing with children with tracheostomies was more common.

> *"So, like, you only get competent the more you see the patients, don't you? .. you go on the trachie study day and then you're expected to see so many patients to get signed off in order to be classed as competent for your trachies, but in this setting [emergency care], they're almost quite few and far between and then we'll have like little flurries, so you tend to get quite a lot of trachies through and then some where you feel like you don't see a trachie for ages, so I think if it's been a little while and say you get a pre-alert for a trachie venting in resuss [Resuscitation], you think "oh God, it's been a little while", and you sometimes run through that thing in your head where you're being like "what am I doing?" So, I think that's probably the biggest challenge" (HCP 14)*

Systems and processes

Although individual level determinants on the experiences of caregiving were distinctly different between HCPs and parents, there were some key influences on the experiences of caregiving that were shared, albeit with different impacts on both groups. There are key structures and processes associated with HCP and carer training and support, including the sign off of required competencies, hospital discharge, respite care packages, and ongoing support that form a key part of the experiences of caring. These processes are subject to organisational level influences, as well as those originating from the wider socio-political, environmental and wider healthcare provision context. For example, where the family lived was reported to have an impact on the health and care support available. Variation in provision and capacity across local authorities, who in the UK are responsible for providing funding and availability of respite care support, as well as differences in the capacity and management of local community nursing teams commissioned by secondary care trusts, presented different experiences for parents from different areas, as well as challenges to the HCPs supporting them. Distance of the family home from the tertiary care hospital, in some cases, could also influence the experience of parent caregivers due to the impact travel time and costs, as well as variable access to healthcare providers with expertise in tracheostomy care in an emergency. One HCP suggested that standardised minimum care quality standards would help to address the "lottery" of system variability and its impact on families.

> *"I think it can be a bit of a, a lottery as I say to, you know, sometimes who shouts the loudest gets the most. Maybe it's where they live, or, you know, kind of all those little things that might affect funding…. things are very different from area to area and, you know, should we have those basic sort of quality standards, , … should there be a minimum requirement for, the input in the care that these children and families receive, … it can be so hit and miss." (HCP 3)*

Examples were provided by some HCP participants highlighting recent improvements in practices to address variability, particularly around training. Box 1 includes example quotes that help to illustrate accounts of the challenges and sub-themes associated with the variability in access to support and care. The impact associated with changes to these systems and processes that were specifically as a result of the Covid-19 pandemic and the need for infection control, such as restrictions on visitors and PPE requirements is described in more detail elsewhere (Hall et al., 2021).

Box 1 –Variability in care and services

Sub-theme	***Example quotes***

Financial support packages and respite care	*"it's very variable about how much care package you get, depending on where you live. It's not standardised… if you live in [place X], you might get a bigger financial package and more hours [respite care support] than if you lived in [place Y] and it just doesn't seem to be any rhyme nor reason towards that, it's just dependent how much money and how many children who have got tracheostomies with special needs in the area" (HCP 7)*
Quality of care	*"everything is always a constant battle. . The same with even getting an OT out. At the moment we've got two fantastic OT's who are really on the ball, which is great, but they don't tend to stay more than a year. We had...there's such a fast turnover in the system of- all specialists. It's the constant change that can be an issue a lot of the time." (Parent 9)* *"in hospital you become so dependent and reliant on people around you.. and suddenly .. It was just like, hospital into home with carers who wouldn't have a clue how to care for a goldfish.. Let alone a child with a trachie" (Parent 5)*
Access	*"me and my husband both feel that we always say that we're really lucky to live where we live and to have the [name] hospital as our local hospital … we've got access to such um you know specialist in our area, so we do feel very, very lucky .., we've always said that the level of care that we've got there has been so high, that we're just lucky that we live close-by" (Parent 7)*
Training provision	*"We have quite a junior staff base. We get quite a lot of newly qualifieds in, and I think trachies are the one thing that I feel like everyone is pretty scared of when you haven't got experience of them. And so I think until you get some supported learning and some supported practice with the trachies, they seem like a bit of an intimidating thing, which you can imagine [pause] for parents must be really challenging when you're coming into an environment where – not that the parents would always know that, but I think as a department we're quite good at now trying to get people on their trachie study day quite quickly." (HCP 14)*
Staffing, skills and capacity	*"It's very much kind of potluck, but when you're a junior nurse, you may end up being more competent quicker than somebody else that you started with on the same week, just because the, the mentor that you're working with, um, you just so happen to be getting more tracheostomy patients than somebody else. So, it's just… luck of how often you get these patients, but how quickly you build up your skills and confidence in looking after these patients." (HCP 12)*

Navigating and negotiating the shared care space

Children with tracheostomies often have a range of other complex care needs and require involvement from a number of different secondary and tertiary care specialities, community care, social care (including independent care agencies) as well as general local hospitals and primary care practitioners. For children of school age, training in tracheostomy care is also provided to staff in nursery and school settings. This involves the navigation of complex health and social care systems and negotiation around the shared care space. The processes and structures described in the section above are primarily aimed at enabling transfer of responsibility of day-to-day medical care of children with tracheostomies to their families and other carers. For many the transfer of responsibility seemed to have been an accepted and taken for granted assumption, rather than an explicitly negotiated shared agreement. Key sub-themes relating to the negotiation required within this complex shared care and cross-organisational space included communication, relationships, trust, empowerment and other power dynamics.

There was recognition within HCP and parent accounts of the importance and value of the expertise of parents in relation to the care of their child and the complexities and challenges around the sharing of medical expertise and shifting of responsibilities over time. This could also at times be incongruent with expectations and traditional norms around parenting roles and responsibilities.

> *"when we were doing the training, the nurse – I remember the nurses like quite vividly saying "you're going to be the experts at this soon", and [father's name] and I laughing, because I thought they were joking… but they were right" (Parent 4)*

From HCP perspectives, an emphasis was placed on empowering parents to be able to care for their child on their own, whilst ensuring they were able to meet the required training competencies in tracheostomy care.

> *"we always try to sort of empower the parents to take on the activities, once they feel able to do that rather than just being a spectator and, you know, the nurse coming in and washing and dressing the child and giving them medication, and maybe the play team come in to play with the child, it's like, well you're the mum and you're the dad, you would've been doing all of this. So it's very much about sort of empowering and sort of acknowledging their role, they are still the mummy and the daddy, and they need to look after this child, and helping them do that, but, so it's a really kind of emotional time. (HCP 13)*

Shared care and responsibility could, nevertheless, at times involve an unspoken and complex negotiation of power and trust that needed to be navigated in varying ways across different professionals, hospital departments and healthcare settings.

> *"I was asking them [the nurses] at first but then .. as time went by I just thought right I'll bath her (baby) I'll do it all myself and then I'll give her a trachie change. And then they would come over and they're like 'oh has she had her trachie changed'? then that would knock me because I'd think 'oh god should...did they need to know that I was doing that'? ... They weren't saying I was doing anything wrong, do you know what I mean? But it, do you know when you start to doubt yourself thinking 'god should I have passed that by them or...'?"* (Parent 14)

> *"The parent is very much the expert and I think we have to be guided by that quite a lot on here, which can be maybe a bit of a challenging thing to get your head around initially, because you feel like you're the one who's supposed to be like managing, .. I think I always adopted the approach of, like, just be really transparent about it. Like talk to the parents about what's their child's normal. (HCP 14)*

All parents over time seemed to recognise the importance of their role and their contribution their expertise in caring for their child brought to their overall care and their need to advocate for their child.

> *" it's so important for a doctor in general to listen to parents and the way I try to describe it to doctors, is that they're the expert in medical needs and how the body works and what things need to be done to keep the body working well.. but I'm the expert in [Child name]" (Parent 20).*

Lack of trust and previous negative experiences of not being listened to, or their knowledge not being acknowledged, meant that many parents felt strongly that they needed to advocate for their child to ensure they received the quality care required.

> *"[child's name] cannot speak out, so I have to be her advocate to make sure that things go well for her." (Parent 8)*

Being listened to and valued was seen as positive by parents. For one parent, who has been involved in a training event for HCPs, and for HCPs, there was acknowledgement of the value of sharing experiences (see box 2).

Box 2 – Sharing parent experiences

Value of shared experiences
"I tend to talk them through .. just, kind of, the curveballs we're thrown and how as a family we deal with that and how it's important that we're listened to whatever ward we end up on, because obviously I've talked about how ward [paediatric respiratory] know [child name] inside out, but that's not the only bit of the hospital. We have to go through the A&E

where the nurses aren't all trachie trained and just kind of explain our experience of that, because there has been some hiccups" (Parent 4)
" I honestly thought it [parent talk] was possibly the best thing of the study day because it – it's that – you forget – you don't forget but it's that –this child is that family's most precious thing and they're a really complex child and this is, this is what they have to contend with every day and it takes a lot for them to give that over to you when they're concerned, especially if something has happened which they haven't… so it was something along the lines of the child – somebody was trying to put them on their circuit, on their wet circuit, but ended up trying to put an oxygen port on their blow off... and obviously the parent was like "no, no, don't do that", that's what this family go and talk about and the learning that you get from somebody who's gone through something like that because it seems practical sticks with you a little bit longer. It also probably scares you a little bit, but I think that's a good thing. (HCP 14)

Parents who had been caring for their child at home were also routinely relied upon to provide tracheostomy care within healthcare settings. Parents' narratives included examples of negative experiences that had resulted in a lack of trust and a need to check that the HCP looking after their child was competent in tracheostomy care.

> *I've noticed when parents know that you're tracheostomy trained and experienced then they're a little bit more relaxed and are happy to kind of leave.. um they can then go and get a little bit of respite as such." (HCP 5)*

This additional burden and responsibility tended to be an accepted and expected part of caring for a child with a tracheostomy and was subject to variation across different care settings. Box 3 includes quotes that exemplify how reliance on the expertise of parents can be influenced by a lack of standardised training, infrequent exposure and the need for different care routines.

BOX 3 – Expert parents

"And the parents are appropriately trained… but, healthcare professionals aren't being trained to the (tertiary care hospital name) training standards. I think that we're not being offered training days, we're not being offered training-up dates… obviously there'll be new student nurses qualifying who may be looking after a child on a ward with a trachie. We're, often relying on parents, because parents tend to do self-care when the kids come in. So they'll do the trachie changes, secretions, and if the trachie blocks the parent is there to change the trachie. .. The nurses know how to use the machines…but my understanding is that often it's the parents who, erm, who, who get things set up because that's part of their routine and they, they keep going in hospital. They don't change that routine. .. The parents are absolutely the experts. (HCP 2)
"And then, she started going downhill, down...they [hospital staff] didn't actually know how to change the settings on the ventilator. They didn't know how to up her pressures. I did,

	luckily, cos I watch when I shouldn't.. So, I had to show them how to do it and then they upped her pressures and then they transferred her to the (hospital name).. (Parent 16)
	"Over the years you see adults occasionally but honestly, this is so rare that, you know, there's no... you know, you have got loads of experience. I've been a GP for thirty years and they, you know...er, you know, I've seen individuals and but often adults will be um experts in their own trachies.. the mum of this little boy [with a tracheostomy] would be the expert if, you know... I would just have to ask her the questions. (HCP 15)
	I think, erm, it's quite interesting though, that on, on occasions where I've phoned an ambulance for a child before, erm, ambulance crews aren't, like, trained to care for children or people with tracheostomies, so then they sort of heavily rely on the parent or, , you know, us in the first instance to kind of actually guide them through, , what we need them to do, if you like. (HCP 3)

The importance of good communication and building relationships that support trust and enabling a collaborative approach to shared care was highlighted by many of the HCPs and parents alike. See box 4.

Box 4– Relationships, communication trust and continuity of care

Continuity of care	*"I think having those relationships, it's really important, especially, as I say, for children like [child's name] , that they have time to get to know the staff and the staff, we were going into A&E once … and I always remember the girl was called (name) I think she's a Ward Sister there now, and she just went straight away, 'I'll get you into a side room because I know [child's name] doesn't like lots of strangers' and as we walked into the room she turned the lights out and she went, 'She doesn't like bright light neither, does she?', and I was like, 'Thank God we've got somebody here who understands and remembers, they know and could remember visits in the past when I'd said, 'Can we lower the lights, because she struggles in a really bright light?'…, that made a massive impact for us and our visit on that day…and it's that, it's that kind of, it might seem a small thing but it's huge, it's huge to parents to know,.. (Parent 8)* *'I'm going to be seeing So and So, I can ask them anything that, you know, they'll not think I'm stupid if I ask what I consider to be a daft question'… as parents, if it's something new you need to and if it's got to be done in a particular way you need somebody who has got that relationship, can go, 'Hang on a minute, no, that's, that's not right, don't do it like that… because this could happen'… but if you've got somebody who you've got a relationship with,…who you trust .. then you can, you can have very honest conversations and sometimes that's what needs to happen from both sides. (Parent 8)*
Communication	*"I think communication is probably the key to everything. ..communication between professionals, between professionals and the family, and in a way that everybody understands." (HCP 13)*

In the region from which our interviewees were based, a paediatric tracheostomy specialist nurse had been appointed to help provide oversight over family and HCP training, care standards, support with communication and coordination of care needs across health and care settings, and providing continuity of care and a key point of contact within a complex care system. This role was valued and was also seen to be important in avoiding over-reliance on parents as communication conduits between different elements of the healthcare system (See box 5).

Box 5 – Importance and value of specialist tracheostomy nurse role

Value of specialist tracheostomy nurse role
" you need to have more (specialist nurse role) because…she's the only trachie expert in the hospital... So, I think, you know, if you had other, possibly another two people who were trained, ready to step into that role, erm, and also to be there so parents get to know them before a change happens, erm, so that you can build that relationship… if you just have a child who was coming in who didn't have any additional needs, was poorly, was getting a trachie, and you hadn't been in the hospital system before, it, it can overwhelm you. So, I think … the most productive relationships are the ones that are based on trust and familiarity, so you know the person when you're coming in, that's a big thing and it's a big thing for the children as well, to have somebody in that continuation. Not to be chopping and changing all the time." (Parent 8)
" once they're discharged, we sail along and if things are going smoothly, we probably don't need to have that communication very much with the hospital. The parents tend to tell you what's happening. So they're... you know, we're going back in for a study or we're going back in for a review or the trachie needs upsizing. So that... we tend to just get that all from the parents. Um but I must say, the last few months, [name], the specialist nurse, has been much more forthcoming and, and giving us information that we would never have normally had". (HCP 16)

Key Mediators

The examples provided in the sections above also provide reference to some key mediators of the experiences and outcomes of caregiving for both parent and professional caregivers, such as coping ability and styles; self-efficacy; availability of and, or access to physical resources such as equipment, funding, training and respite care; and social support.

Parents described how ongoing communication and relationships with HCPs become an integral part of everyday life. Most children, particularly those with other complex medical needs, are seen by a wide range of HCPs. This was often associated with practical difficulties in managing multiple appointments and perspectives. The need for respite care, either from extended family or other social care providers was, however, a key challenge for families and played a key role in parents' experiences of caregiving. Access to and perceived value of online forums and support groups was variable,

however, when available, social and informational support from other families with similar experiences was reported to have had a range of positive impacts, including health outcomes for some children as well as emotional and physical health of the parents.

Tracheostomy carer training ensures parents have sufficient knowledge and met standard core competencies for meeting the physical care needs of tracheostomy care, however, perceived preparedness for other aspects of care and support with the burden of care was more varied. For example, psychological support was unavailable to many parents, or was only available through other routes such as through other hospital departments, including the special care baby units. Support with accessing and dealing with the management of respite care arrangements via local authority care plans, or the organisation of multiple multi-disciplinary specialities appointments and follow-up plans was also reported to be inconsistent (See Box 6).

Box 6 – Mechanisms of support for parents

Sub-theme	Example quotes
HCP support	*"I had to push to be, escalated to the (name) hospital and [get the] support that I've had. .. but (consultant name) and (name) and the two of them that are just, the most amazing support that was offered to me…Even after, after her trachie do you know what I mean these two people, well not (name), cos I haven't seen (name) for a while but (consultant name) He understands and I think it was having someone believe in you and understand you made it easier to then look after my daughter. Cos I just didn't feel like it was all going wrong and I was getting it wrong and like other people knew better than me.." (Parent 5)* *"one of the problems you can have with a tracheostomy is over grannulation. unfortunately normally community nursing teams are meant to deal with that but our community nursing team don't [offer specific treatment] … [specialist nurse] actually came out to our home and did the treatment at home, which was fantastic" (parent 19)* *"they do listen.. the individual teams at [hospital name] seem to do that quite well and work together...what the problem is is that once you come outside of that one hospital, it doesn't come together as well.. that working together and taking account of all the, all the other needs together, isn't there as much" (parent 20)*
Respite care	*"we had like an MDT in the hospital and it was agreed that we'd need a carer to come and help with (child's name) 's care at home because obviously we've got another little one as well. It was agreed that [child's name] could access respite facilities, um and this was all before the [covid-19] lockdown. So when we did get home, all of that discussion and all of those plans were put on hold because we couldn't get any carers and it was due to the training, we couldn't get anybody to the house, we couldn't access respite" (Parent 3)* *"it's difficult. Erm, which is probably why we've managed to stick with one carer. We've had a few others come and go. Erm, that were kind of...you know...like*

	[carer name]'s relief workers really and its awkward for everyone all round, isn't it really. Having someone else in your home, but you tend to just get on with it, and like I say, if you click with that person then it-it works out…Yeah, she's just like another family member now. [laughter]" (Parent 9) *"if we don't have [respite] care, if we've been up all night... meeting [child's] care needs, how are we able to meet their care needs the next day? Me and the wife have both had treatment from the doctors for exhaustion.. we've both got one or two health conditions, since we've been caring for [child]. Before, you know, I was fairly healthy.. I've got to lift him everywhere ..because of that I've er injured my neck and I've got constant pins and needles down the left hand side of my body" (Parent 20)*
Online groups and support from other parents	*"I think as time's gone on it's all the practical things, I've found that Facebook [tracheostomy] support group really, really useful and there's things that I've learnt from there that I wish somebody would have told me early on."* (Parent 7) *"Most of them seem to end up on social media and go on to some scary Facebook page. So we try and avoid them to do that. We try and sort of say, look, at this one first, some more factual information and then some of them will just naturally then head towards Facebook groups for support." (HCP 8)*
Other Social support	*"It depends on the families and it depends on the support systems they've got in place at home because I think if they've got family that are good and support them and happy to help out in any way, then... but I must admit, the last six months have been hard for families, haven't they? Covid, not being able to get anyone else to, to give them a break. (HCP 16)*
Psychological support	*"we don't have a psychologist on our ward for parents, which absolutely makes no sense when there's a psychologist on most wards for, not minimal, but to our, our standard, minimal things. So it's the parents that are dealing with the child that's going to die and they have no psychological support, which is just ludicrous. We don't understand it. Apparently, there's no funding for it and for us to have one. So I feel like, if we had a psychologist, they would definitely feel... it would be nice to have someone who wasn't..., that's always around them and to just talk through the situation, not from a medical point of view, just, you know, like first from a psychological point of view from the parents... (HCP 17)* *" I had to arrange it [counselling] myself. I went for an assessment with the perinatal mental health team in [name] hospital and they wanted us to, seek some support at the [name)] hospital from the psychologist on the trache team, but I wanted something that was completely separate to [child name]. I don't want… like, what I'm talking about to, to be linked with [child name]. For me the [name] hospital has got a lot of bad memories, so I didn't want the memory travelling to the [name] hospital for whatever support..... so I've gone private with it." (Parent 17)*

For HCPs, a key mediator was the support they received from their immediate work colleagues as well as wider multi-disciplinary teams. This played a key role across all settings in their experience of, and

confidence in, providing high quality care to children with tracheostomies. Narratives suggested that communication and relationships between health professionals is critical in supporting shared care, burden, responsibility and decision-making and is stronger within, rather than between, health and social care setting boundaries. The specialist nurse role mentioned above was seen to provide a valuable addition to helping improve access to standardised information and training and supporting communication between different care teams. Professional networks were also seen to offer reassurance and provision of up-to-date knowledge. Established clinical pathways, protocols and processes around all key stages of caregiving (e.g. from assessment, decision to tracheostomise, training parents, discharge and follow-up) were also important mechanisms for supporting HCP roles and key to facilitating self-efficacy. Box 7 provides examples of how different types of support can impact on HCPs experiences.

Box 7 – Mechanisms of support for HCPs

Sub-theme	***Example quote***
Team working	*"if we have difficulties at a weekend and I was really struggling with a problem I'm sure one of them [other members of the team off duty] wouldn't be concerned if I gave them a call and asked for advice, or even you know to come in and give me a hand if there was a particular issue. So, we have a good support network." (HCP 1)* *"think some of the challenges will be in… in terms of making that decision, and making sure that you've, involved the parents fully in the discussion. you'll… kind of, go through the different options that might be available, , you've explored those options, you've discussed with, like, the relevant teams. You know, whichever teams… other teams might be involved. So as a collective, I suppose you can come to, an understanding and a decision about what's in the best interests what's needed for the child at that time." (HCP 10)*
Professional Networks	*"you can gain an insight in terms of what's going on, , nationally, I suppose, through discussions that you might have with peers, or at, conferences, or other events that you might attend, … and there's an opportunity to attend, study days"* (HCP 10)
Clinical pathways and protocols	*"having a protocol has really helped, so everyone does the tracheostomies in exactly the same way, in a very stepwise manner. … that really helped me in terms of my understanding and learning of the steps, is that I always had that structured method of doing things.. it's not sort of a national protocol, but everyone works along the same sort of guidelines."* (HCP 9)

Training and exposure	*"so there's the trachee study day, which is delivered or arranged by the airway specialist nurse, so there's that training. but kind of training as an OT [occupational therapist] sort of from university, you, you wouldn't get any specialist training. I think most of it is kind of learning on the job, and any in house training that you, you can be party of and, you know, the specialist nurses are very good, and are very willing to kind of go through things, and, you know, should you need to know like a, anything more." (HCP 13)* *"I think the trainees are getting more exposure to more complex paediatric ENT procedures than they used to. I think that is certainly something that is good and compared to it was say ten years ago". (HCP 11)*

Key challenges described, however, included variable capacity of teams and differences in expertise and experience across departments and even in some cases, shift patterns. Some HCPs found dealing with the emotions of parents and children more challenging than others, this seemed to be partly due to individuals but also to expectations relating to their professional roles. The following quote explains how this can be affected by a range of factors, including the needs and age of the child.

> *"I found that a lot harder because it, not only were you dealing with the parents' anxiety and fear, but hers as well, um, because she was that much older, she'd got all of this experience of not needing a tracheostomy. So she was really fearful, she was really anxious. Every time we would come near her, I mean I can't even begin to imagine what the, the feeling of having a tracheostomy suctioned, you know, it must feel horrendous, so, and you could see it on her face. She, she was just terrified the whole time that we were near her. .. a few of us went down to see on the ward afterwards and she'd totally got used to having that tracheostomy but I think, for me, it was just seeing that fear in her face " (HCP 12)*

Impact

As illustrated in Figure 1 and described above, reported experiences of caregiving includes wide-ranging impacts on the caregiver, the child, and in some case also immediate and extended family, including siblings, grandparents, etc. The burden of care on parents had far-reaching impact on all aspects of their and their families' lives, including their psychological and physical health, quality of life, and employment opportunities, as well as the cultural and societal norms and expectations associated with parenthood. These experiences in turn can influence their perceived ability and

capacity to cope, which can then reinforce and further impact negative effects of stress on health and wellbeing and the capacity and ability to provide quality care.

Although a number of challenges were described by HCPs, there was little perceived impact of providing care for children with tracheostomies, due mainly to this being an expected part of their professional roles. Where emotional impact was reported, this was not seen to be specific to caregiving for children with tracheostomies and often described as "part of the job". Although impact was not a major theme in the HCP accounts, when it was mentioned, this related mainly to confidence, perceived quality of care provided and job satisfaction.

DISCUSSION

In line with theoretical frameworks for understanding the impact of informal caregiving [29], our findings highlight key determinants (family capacity and ability; health provider capacity and ability; system factors; and factors relating to the interface with the health and care system) and mediators (coping and appraisal; self-efficacy; physical resources; and social, team and professional support) that influence how people deal with caregiving and the impact this has. For parents, access to care packages and respite care at home are key influences on their experience and quality of life. For HCPs, the importance of multidisciplinary team and colleague support, established clinical pathways and processes, and access to training and updates were most important. The related impacts of caregiving (such as psychological and physical health and quality of life of parents and their families, and confidence and perceived quality of care) can in turn influence re-appraisal of the situation, self-efficacy and coping resources. This is in line with established evidence and theory on stress and coping, whereby, with any response to a potential threat or stressor, there is an ongoing process of reappraisal of an individual's initial or primary appraisal of the threat as well as the resources and coping strategies at their disposal to respond to it. [33]

Our findings map closely to the constructs included within the Informal Caregiving Integrative Model (ICIM) [29] which informed our initial coding framework. Although this model was developed to explain informal caregiver burnout, which was not a key focus of our study and did not appear in the narratives of HCPs, we feel that the processes and constructs within it were able to be more widely applied to the general psychological and emotion impact of caregiving in this context. Our analytic approach was therefore theoretically informed but allowed flexibility and ensured that emergent themes reflecting the voices of our participants were incorporated into our coding framework and findings.

A key theme threaded throughout our findings was the lack of standardisation of many aspects of health and care settings in which caregiving experiences were situated and the ad-hoc nature of some key mediators. Examples included: geographical variation in access to different support teams, care packages and respite care; differences in access to regular training and updates; variation in health provider expertise and experiences across roles, settings and even shift patterns, which can be exacerbated in healthcare settings with limited frequency of contact with children with tracheostomies. Other wider policy and organisational influences included resource and funding constraints, existing relationships and communication between primary, community, secondary, tertiary and social care. As a consequence of the timing of data collection, the Covid-19 pandemic, was also a key theme and this has been described elsewhere. [30]

Our findings concur with previous work highlighting the significant burden placed on parents who care for children with complex medical needs, and in particular children with tracheostomies. [7 8 10 17] Negative impacts on quality of life, physical and mental health and family function have previously been reported in families with children who rely on medical technologies [15 21] and tracheostomies more specifically [7 20]. This includes effects on sleep, relationships, social life and ability to work [10]. Our findings also complement qualitative research from other countries focused on specific experiences, such as decision-making around tracheostomy procedures and risk communication, [12 18 19] transition to home, [20-23] home care, [34] social support, [35] and health care seeking. [36] These studies have focused mainly on the experiences of informal caregivers and on intensive care settings. [25] Our study included a range of perspectives from families with children of different ages, care needs and time since tracheostomy, as well as the inclusion of perspectives of a range of HCPs, and a focus on the interaction within the shared care spaces across health care and home settings.

Findings from UK based studies have previously identified a need for regular revision of skills and information around paediatric tracheostomy clinical care for informal carers [9 10] and HCPs [13]. A need for improved tracheostomy education among paediatric HCPs to help improve knowledge, confidence, and skills has also been identified in the US [37 38]. Our findings suggest that standardised and regular training provision and availability, in particular for HCPs who do not have consistent exposure to providing paediatric tracheostomy care still remains an issue.

A recent qualitative phenomenological study focusing on the facilitators and barriers to the tracheostomy decision-making (TDM) process [18] highlighted the importance of communication and team working. Our findings suggest that this is an important aspect of the caregiving experience for families and HCPs across the entire tracheostomy care "journey". We also highlight the challenges associated with clinical care responsibilities being transferred to parents and the need to acknowledge

and include parents as experts. Our findings concur with those from a qualitative study on the experiences of parents of children with rare diseases [39], other complex health conditions [40-42] or who require complex medical care at home [15], whereby key challenges for parents were navigating the healthcare system and the added burden of the additional role of care co-ordinator. Work in the US and Canada has shown that the use of patient navigators [43] or family centred care coordination [44] can be helpful in supporting patients and their caregivers in navigating the healthcare system to improve access and integration of care and improving quality of life.

Findings from a study exploring the mechanisms through which an interprofessional team approach can improve the management of patients with a tracheostomy found that communication and the use of standardised practice protocols were important. [14] We are not aware of any research that includes family carers as experts within the MDT team and Baumbusch, et al. [39] highlight that parents' roles as expert caregivers are rarely acknowledged by HCPs. In contrast, our findings suggest that this was a fairly widely accepted narrative across our HCP sample. For example, there was a reported acknowledgment of reliance on the expertise of the parents in the tracheostomy care of their child across a range of healthcare situations and settings, particularly when HCP expertise or knowledge of individual children's care needs are lacking. How to negotiate this complex power dynamic was not straightforward and is not often explicitly addressed. Kirk [45] proposes that expectations of parental involvement, feelings of obligation and a lack of community resources can act as barriers in negotiation of care roles and that it is important that changes in power dynamics and parent-professional relationships are based on partnership rather than conflict. Our findings highlight how this process is also likely to be closely intertwined with parents' navigating their own biographical disruption as a result of their child's needs and what it means to be a parent, particularly when expectations and responsibilities normally associated with parenting is temporarily taken over by HCPs, as also described in previous work with parents of children with mental health conditions.[32]

The importance of standardisation of care and training to help improve care quality has been previously highlighted [46]. Initiatives such as the Global Tracheostomy Collaborative (GTC), [47], and work looking at the potential of virtual and online training as a result of the Covid-19 pandemic [48] may help address some of these issues in this setting. In England, the multi-disciplinary National Tracheostomy Safety Project has developed a standardised universal approach to improve the management of tracheostomy and laryngectomy critical incidents [49 50]. However, there are currently no paediatric tracheostomy specific service specifications, which are clearly defined standards of care expected from organisations funding by NHS England to provide specialised care for certain specialist conditions or interventions. This means that the levels of care and support are only defined on a local level. We would advocate the development of a paediatric tracheostomy service specification, including

extensive multidisciplinary support. Children with tracheostomies often have a range of other complex medical needs, so it is important that the challenges of families in navigating the complexities of shared care arrangements, appointments and support across hospital departments and different health and care organisations are taken into consideration. Our findings suggest that a key area to be addressed for families is accessing funding support, care packages and respite care across different local authority areas. This does not seem to be specific to the UK and has been identified as an issue elsewhere. [51] In addition, supporting access to formal psychological support for families, and wider social support more generally, may also help mediate the consequences associated with burden of care. [52] Supporting the emotional needs of parents and children was also one of the areas that HCPs found challenging in our interviews. Emotional support has also been identified as one of the key areas carers feel needed to be addressed in tracheostomy care training.[9]

The interviewees in our study were recruited from a region covered by a tertiary care centre benefitting from a fairly recently implemented paediatric tracheostomy specialist nurse role supporting HCPs and families. This type of role may help address challenges associated with some important mediators of the caregiving experience and quality of care identified in our study, such as the availability of standardised clinical pathways, processes and guidance, as well as relationships, teamwork and communication across families, health, care and educational organisations supporting children with tracheostomies. Such roles may also be beneficial for developing trust and providing a key point of contact and supporting continuity of care, which has also been highlighted as an important issue for parents caring for children with other complex chronic health conditions. [40 42]

Further research would be required to assess whether national standards of care, or the expansion of novel specialist nurse roles, or changes to training provision may help to improve quality of care. Multiple measurable outcomes could be used, such as reducing the significant healthcare utilisation and cost burden associated with hospital readmissions in children with tracheostomies [2] or outcomes such as morbidity, mortality, quality of life for children and families.

Limitations

Despite clear evidence of open and honest accounts from all participants, it is likely that health care providers may have felt sensitive about disclosures that could have been linked to the provision of care or professional practice that may be perceived to be sub-standard. Interactions within focus groups may have provided additional understanding around shared experiences than our individual interviews were able to. Due to the demands on caregivers' time, interviews were chosen for pragmatic concerns to allow more flexibility to fit in with individual availability. As data collection took place during the pandemic restrictions, all interviews were completed over the phone or online which

may have influenced participation and engagement. Only three of the parents who agreed to be interviewed were fathers. This is likely to be reflective of the tendency of responsibility for care to be gendered. [31] Although training in tracheostomy care is required by all parents, our findings reflect those of Harden [32] that even in dual-parent families, the mother tended to generally be the primary carer and was usually, but not always, the main point of contact with health and care services. Further research around the impact of caregiving in this setting on parenting roles, including consequences on employment and financial security, identity and biographical disruption may be valuable.

Inequities associated with respite care and associated funding and resources were important themes throughout the interviews. HCPs included were from health care settings and professionals and informal care givers from social care and education settings were not interviewed. These are likely to have different experiences and needs. Exploring these different perspectives may provide additional insight and be a valuable avenue for further research. Our study includes experiences of caring for children with a wide range of complex care needs that have a tracheostomy. The complexity of their care needs was a key factor in experiences of caregiving and although we were confident that no new themes were emerging from our final interviews, our findings may not be representative of all carers' experiences. Furthermore, our study was completed in a region in England served by one tertiary care centre and may not be fully transferable to other regions.

CONCLUSION

Our findings highlight some theoretically informed issues specific to caregivers of children with tracheostomies that are also likely be of relevance to carers of children with other complex medical issues. Integration of perspectives from both informal carers (parents) as well as formal HCPs can help to understand how to support system level changes to improve the experience of caregiving by improving communication and relationships and reducing the burden and potential psychological and physical impact on informal caregivers. We advocate the development of a paediatric tracheostomy service specification, including extensive multidisciplinary support that accounts for identified key priorities, including recognition of the involvement and expertise of parents, training and ongoing education needs of health care providers and families, increasing use of paediatric tracheostomy specialist nurse roles, and addressing the emotional and psychological support needs of caregivers.

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Ethics approvals

This study involves human participants and was approved by the HRA Ethics Committee reference 20/WM/0025. Participants gave informed consent to participate in the study before taking part.

Author contributions

JP, NR, MB, DH, AJS and SP all made substantial contributions to the conception and design of the work. NH and JP were responsible for data collection, analysis, interpretation of data and leading on drafting the paper, with contributions from NR, DH, MB, AJS and SP around interpretation and revising the work critically for important intellectual content. JP acts as guarantor and accepts full responsibility for the finished work and the conduct of the study, had access to the data, and controlled the decision to publish.

Competing interests

The authors have no competing interests to declare.

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Data sharing

Data is not available freely available for sharing to protect anonymity of study participants. The authors will consider any reasonable request for data sharing where appropriate.

REFERENCES

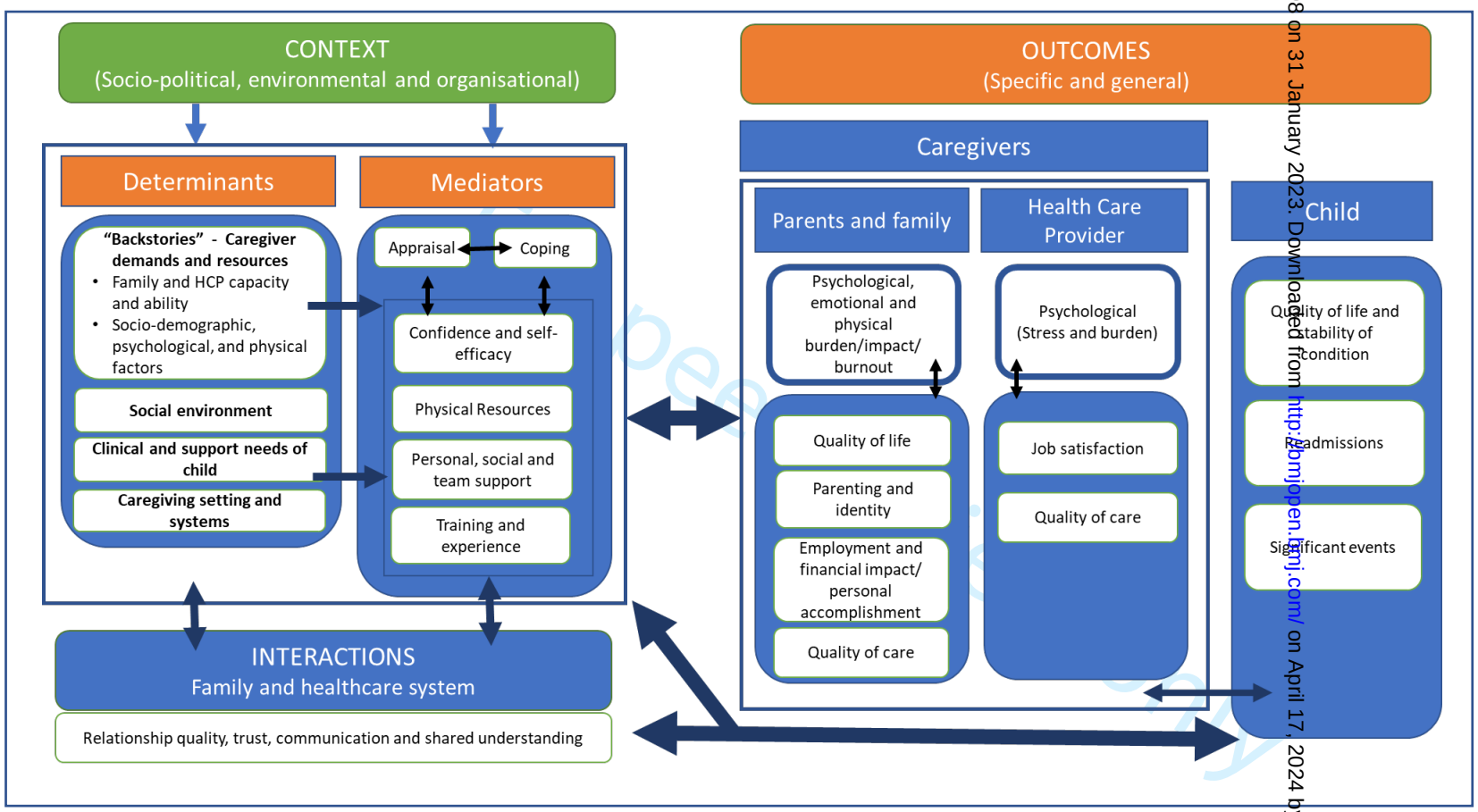
1. Powell J, Buckley HL, Agbeko RS, et al. Tracheostomy trends in paediatric intensive care. *Archives Diseases of Childhood* 2021;106:712-14.
2. Powell J, Keltie K, Sims A, et al. A national cohort study of healthcare resource utilization following pediatric tracheostomy (in press) *JAMA Paediatrics* 2022
3. Roberts J, Powell J, Begbie J, et al. Pediatric tracheostomy: A large single-center experience. *Laryngoscope* 2020;130(5):E375-E80. doi: 10.1002/lary.28160 [published Online First: 2019/06/30]
4. Perez-Ruiz E, Caro P, Perez-Frias J, et al. Paediatric patients with a tracheostomy: a multicentre epidemiological study. *Eur Respir J* 2012;40(6):1502-7. doi: 10.1183/09031936.00164611 [published Online First: 20120410]
5. Watters KF. Tracheostomy in Infants and Children. *Respir Care* 2017;62(6):799-825. doi: 10.4187/respcare.05366 [published Online First: 2017/05/27]
6. Fiske E. Effective strategies to prepare infants and families for home tracheostomy care. *Adv Neonatal Care* 2004;4(1):42-53. doi: 10.1016/j.adnc.2003.11.011
7. Flynn AP, Carter B, Bray L, et al. Parents' experiences and views of caring for a child with a tracheostomy: a literature review. *International journal of pediatric otorhinolaryngology* 2013;77(10):1630-4. doi: 10.1016/j.ijporl.2013.07.020 [published Online First: 2013/08/21]
8. Flynn A, Whittaker K, Donne AJ, et al. Holding Their Own and Being Resilient: Narratives of Parents over the First 12 Months of Their Child Having Tracheostomy. *Comprehensive child and adolescent nursing* 2020;1-11. doi: 10.1080/24694193.2020.1785046 [published Online First: 2020/07/02]
9. Antoniou I, Wray J, Kenny M, et al. Hospital training and preparedness of parents and carers in paediatric tracheostomy care: A mixed methods study. *International journal of pediatric otorhinolaryngology* 2022;154:111058. doi: 10.1016/j.ijporl.2022.111058 [published Online First: 20220129]
10. Hopkins C, Whetstone S, Foster T, et al. The impact of paediatric tracheostomy on both patient and parent. *International journal of pediatric otorhinolaryngology* 2009;73(1):15-20. doi: 10.1016/j.ijporl.2008.09.010 [published Online First: 2008/11/21]
11. McCormick ME, Ward E, Roberson DW, et al. Life after Tracheostomy: Patient and Family Perspectives on Teaching, Transitions, and Multidisciplinary Teams. *Otolaryngology--head and neck surgery* 2015;153(6):914-20. doi: 10.1177/0194599815599525 [published Online First: 2015/08/20]
12. Nageswaran S, Golden SL, Gower WA, et al. Caregiver Perceptions about their Decision to Pursue Tracheostomy for Children with Medical Complexity. *The Journal of pediatrics* 2018;203:354-60.e1. doi: 10.1016/j.jpeds.2018.07.045 [published Online First: 2018/09/22]
13. Ward E, Morgan T, McGowan S, et al. Preparation, clinical support, and confidence of speech-language therapists managing clients with a tracheostomy in the UK. *International journal of language & communication disorders* 2012;47(3):322-32. doi: 10.1111/j.1460-6984.2011.00103.x [published Online First: 2012/04/20]
14. Mitchell R, Parker V, Giles M. An interprofessional team approach to tracheostomy care: a mixed-method investigation into the mechanisms explaining tracheostomy team effectiveness. *International journal of nursing studies* 2013;50(4):536-42. doi: 10.1016/j.ijnurstu.2012.11.008 [published Online First: 2012/12/12]
15. Page BF, Hinton L, Harrop E, et al. The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'. *Health expectations* 2020; doi: 10.1111/hex.13092 [published Online First: 2020/06/17]
16. Westwood EL, Hutchins JV, Thevasagayam R. Quality of life in paediatric tracheostomy patients and their caregivers - A cross-sectional study. *International journal of pediatric*

otorhinolaryngology 2019;127:109606. doi: 10.1016/j.ijporl.2019.109606 [published Online First: 2019/09/09]
17. Carnevale FA, Alexander E, Davis M, et al. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics* 2006;117(1):e48-60. doi: 10.1542/peds.2005-0789 [published Online First: 2006/01/07]
18. Gower WA, Golden SL, King NMP, et al. Decision Making about Tracheostomy for Children with Medical Complexity: Caregiver and Healthcare Provider Perspectives. *Academic pediatrics* 2020 doi: 10.1016/j.acap.2020.06.004 [published Online First: 2020/06/17]
19. Hebert LM, Watson AC, Madrigal V, et al. Discussing Benefits and Risks of Tracheostomy: What Physicians Actually Say. *Pediatric critical care medicine* 2017;18(12):e592-e97. doi: 10.1097/pcc.0000000000001341 [published Online First: 2017/09/25]
20. Amar-Dolan LG, Horn MH, O'Connell B, et al. "This Is How Hard It Is". Family Experience of Hospital-to-Home Transition with a Tracheostomy. *Annals of the American Thoracic Society* 2020;17(7):860-68. doi: 10.1513/AnnalsATS.201910-780OC [published Online First: 2020/04/09]
21. Brenner M, Larkin PJ, Hilliard C, et al. Parents' perspectives of the transition to home when a child has complex technological health care needs. *International journal of integrated care* 2015;15:e035. doi: 10.5334/ijic.1852 [published Online First: 2015/11/04]
22. Callans KM, Bleiler C, Flanagan J, et al. The Transitional Experience of Family Caring for Their Child With a Tracheostomy. *Journal of pediatric nursing* 2016;31(4):397-403. doi: 10.1016/j.pedn.2016.02.002 [published Online First: 2016/04/05]
23. Toly VB, Blanchette JE, Alhamed A, et al. Mothers' Voices Related to Caregiving: The Transition of a Technology-Dependent Infant from the NICU to Home. *Neonatal network : NN* 2019;38(2):69-79. doi: 10.1891/0730-0832.38.2.69 [published Online First: 2019/08/31]
24. Patel MR, Zdanski CJ, Abode KA, et al. Experience of the school-aged child with tracheostomy. *International journal of pediatric otorhinolaryngology* 2009;73(7):975-80. doi: 10.1016/j.ijporl.2009.03.018 [published Online First: 2009/05/01]
25. Nakarada-Kordic I, Patterson N, Wrapson J, et al. A Systematic Review of Patient and Caregiver Experiences with a Tracheostomy. *The patient* 2018;11(2):175-91. doi: 10.1007/s40271-017-0277-1 [published Online First: 2017/09/16]
26. Corris V, Dormer E, Brown A, et al. Health inequalities are worsening in the North East of England. *Br Med Bull* 2020;134(1):63-72. doi: 10.1093/bmb/ldaa008
27. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 2019;11(4):589-97. doi: 10.1080/2159676x.2019.1628806
28. Altman L, Zurynski Y, Breen C, et al. A qualitative study of health care providers' perceptions and experiences of working together to care for children with medical complexity (CMC). *BMC Health Serv Res* 2018;18(1):70. doi: 10.1186/s12913-018-2857-8 [published Online First: 2018/02/02]
29. Gerain P, Zech E. Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving. *Front Psychol* 2019;10:1748. doi: 10.3389/fpsyg.2019.01748 [published Online First: 2019/08/21]
30. Hall N, Rousseau N, Hamilton DW, et al. Impact of COVID-19 on carers of children with tracheostomies. *Archives of disease in childhood* 2022;107(3):e23. doi: 10.1136/archdischild-2021-322979 [published Online First: 20211209]
31. Read J. Disability, the Family and Society: Listening to Mothers. Buckingham: Open University Press. 2000.
32. Harden J. Parenting a young person with mental health problems: temporal disruption and reconstruction. *Sociology of Health and Illness* 2005;27(3):351-71.
33. Lazarus RS. Stress and emotion: A new synthesis. New York: Springer. 1999.

34. Gong S, Wang X, Wang Y, et al. A Descriptive Qualitative Study of Home Care Experiences in Parents of Children with Tracheostomies. *Journal of Pediatric Nursing* 2019;45:7-12. doi: 10.1016/j.pedn.2018.12.005 [published Online First: 2018/12/31]
35. Lemos HJM, Mendes-Castillo AMC. Social support of families with tracheostomized children. *Revista brasileira de enfermagem* 2019;72(suppl 3):282-89. doi: 10.1590/0034-7167-2018-0708 [published Online First: 2019/12/19]
36. Spratling R, Lee J. Caregivers experiences in symptom management for their children who require medical technology at home. *Journal for Specialists in Pediatric Nursing : JSPN* 2020;25(1):e12275. doi: 10.1111/jspn.12275 [published Online First: 2019/10/19]
37. Agarwal A, Marks N, Wessel V, et al. Improving knowledge, technical skills, and confidence among pediatric health care providers in the management of chronic tracheostomy using a simulation model. *Pediatric Pulmonology* 2016;51(7):696-704. doi: 10.1002/ppul.23355 [published Online First: 2015/12/19]
38. Davis KA, Edgar-Zarate CL, Bonilla-Velez J, et al. Using Didactics and Simulation to Enhance Comfort, Knowledge, and Skills of Nonsurgical Trainees Caring for Patients With Tracheostomy and Laryngectomy. *Simulation in Healthcare* 2019;14(6):384-90. doi: 10.1097/sih.0000000000000392 [published Online First: 2019/12/06]
39. Baumbusch J, Mayer S, Sloan-Yip I. Alone in a Crowd? Parents of Children with Rare Diseases' Experiences of Navigating the Healthcare System. *J Genet Couns* 2018 doi: 10.1007/s10897-018-0294-9 [published Online First: 2018/08/22]
40. Golden SL, Nageswaran S. Caregiver voices: coordinating care for children with complex chronic conditions. *Clinical pediatrics* 2012;51(8):723-9. doi: 10.1177/0009922812445920 [published Online First: 2012/05/09]
41. Cady RG, Belew JL. Parent Perspective on Care Coordination Services for Their Child with Medical Complexity. *Children* 2017;4(6) doi: 10.3390/children4060045 [published Online First: 2017/06/08]
42. Miller AR, Condin CJ, McKellin WH, et al. Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Serv Res* 2009;9:242. doi: 10.1186/1472-6963-9-242 [published Online First: 2009/12/23]
43. Luke A, Luck KE, Doucet S. Experiences of Caregivers as Clients of a Patient Navigation Program for Children and Youth with Complex Care Needs: A Qualitative Descriptive Study. *International Journal of Integrated Care* 2020;20(4):10. doi: 10.5334/ijic.5451 [published Online First: 2020/12/01]
44. Hartnick C, Diercks G, De Guzman V, et al. A quality study of family-centered care coordination to improve care for children undergoing tracheostomy and the quality of life for their caregivers. *International Journal of Pediatric Otorhinolaryngology* 2017;99:107-10. doi: 10.1016/j.ijporl.2017.05.025 [published Online First: 2017/07/10]
45. Kirk S. Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of Advanced Nursing* 2001;34(5):593-602.
46. Tolomeo CT, Major NE, Szondy MV, et al. Standardizing Care and Parental Training to Improve Training Duration, Referral Frequency, and Length of Stay: Our Quality Improvement Project Experience. *Journal of Pediatric Nursing* 2017;32:72-79. doi: 10.1016/j.pedn.2016.10.004 [published Online First: 2017/03/28]
47. Brenner MJ, Pandian V, Milliren CE, et al. Global Tracheostomy Collaborative: data-driven improvements in patient safety through multidisciplinary teamwork, standardisation, education, and patient partnership. *British Journal of Anaesthesia* 2020;125(1):e104-e18. doi: 10.1016/j.bja.2020.04.054 [published Online First: 2020/05/28]
48. Swords C, Bergman L, Wilson-Jeffers R, et al. Multidisciplinary Tracheostomy Quality Improvement in the COVID-19 Pandemic: Building a Global Learning Community. *The Annals of Otology, Rhinology, and Laryngology* 2021;130(3):262-72. doi: 10.1177/0003489420941542 [published Online First: 20200717]

49. McGrath BA, Wallace S, Lynch J, et al. Improving tracheostomy care in the United Kingdom: results of a guided quality improvement programme in 20 diverse hospitals. *British Journal of Anaesthesia* 2020;125(1):e119-e29. doi: 10.1016/j.bja.2020.04.064 [published Online First: 2020/06/05]
50. McGrath BA, Ashby N, Birchall M, et al. Multidisciplinary guidance for safe tracheostomy care during the COVID-19 pandemic: the NHS National Patient Safety Improvement Programme (NatPatSIP). *Anaesthesia* 2020;75(12):1659-70. doi: 10.1111/anae.15120 [published Online First: 2020/05/13]
51. Keilty K, Nicholas D, Selkirk E. Experiences with unregulated respite care among family caregivers of children dependent on respiratory technologies. *Journal of Child Health care* 2018;22(1):46-56. doi: 10.1177/1367493517746770 [published Online First: 2017/12/28]
52. Rafferty KA, Beck G, McGuire M. When Facing Hopeful and Hopeless Experiences: Using Snyder's Hope Theory to Understand Parents' Caregiving Experiences for Their Medically Complex Child. *Journal of Pediatric Health Care* 2020;34(6):542-49. doi: 10.1016/j.pedhc.2020.06.003 [published Online First: 2020/08/11]

Figure 1 – Influences on the experiences of caregiving



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Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

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Providing care for children with tracheostomies: a qualitative interview study with parents and health professionals

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Abstract

Objectives: To explore the experience of caring for children with tracheostomies from the perspectives of parents and health professional caregivers.

Design: Qualitative semi-structured interview study

Setting: One region in England covered by a tertiary care centre that includes urban and remote rural areas and has a high level of deprivation.

Participants: A purposive sample of health professionals and parents who care for children who have, or have had, tracheostomies and who received care at the tertiary care centre.

Results: This paper outlines key determinants and mediators of the experiences of caregiving and the impact on psychological and physical health and quality of life of parents and their families, confidence of healthcare providers, and perceived quality of care. For parents, access to care packages and respite care at home as well as communication and relationships with health care providers are key mediators of their experience of caregiving, whereas for health professionals, an essential influence is multi-disciplinary team working and support. We also highlight a range of challenges focused on the shared care space, including: a lack of standardisation in access to different support teams, care packages and respite care; irregular training and updates, and differences in health provider expertise and experiences across departments and shift patterns, exacerbated in some settings by limited contact with children with tracheostomies.

Conclusions: Understanding the experiences of caregiving can help inform measures to support caregivers and improve quality standards. Our findings suggest there is a need to facilitate further standardisation of care and support available for parent caregivers and that this may be transferable to other regions. Potential solutions to be explored could include the development of a paediatric tracheostomy service specification, increasing use of paediatric tracheostomy specialist nurse roles, and addressing the emotional and psychological support needs of caregivers.

Strengths and limitations of this study

- By including perspectives of parents and health care professionals who care for children with tracheostomies, our analysis allowed for novel and valuable comparisons to be made around the shared care space.

- The inclusion of accounts from health care professionals from primary, community, secondary and tertiary care allowed rich insight into carer experiences across organisational boundaries.
- Our study took place across one large geographic region in England that covers rural and urban areas and has higher levels of deprivation than the rest of England, however transferability to other settings may be dependent on local service structures.
- We were not able to include perspectives of carers providing respite care and support based in social care and educational settings.
- Despite participant accounts covering experiences from earlier time points, data collection took placed during the Covid-19 pandemic which had an impact on the experiences of care and caregiving.

BACKGROUND

Tracheostomies are performed in children mainly to facilitate long-term ventilation, in cases of airway obstruction or neurological impairment.[1-3] Only a quarter to half of children who rely on a tracheostomy are decannulated, and for those who are, the average time before decannulation is two years. [4 5]

Tracheostomies can be associated with potentially fatal risks such as airway obstruction, mucus plugging, tube displacement, bleeding and infection. [6 7] Parents, professional health care providers (HCPs) and other carers must undergo a comprehensive training programme and competency assessments in order to manage required aspects of care, including providing suction, stoma care, tube changes and resuscitation. [8 9] Training, knowledge and confidence in delivering this type of care, can remain a challenge for parents and health care providers alike. [10 11 12-14]

The burden of care on families caring for children with complex medical needs has been reported to be greater than understood by HCPs or the general public, prompting calls for better preparation and support for families. [15] Quality of life of parents and carers of children requiring tracheostomy, who can also have a range of other complex health care needs, is poor and has been reported to be worse than those with children with other chronic conditions, such as diabetes, cancer and renal disease. [16] Caring for a child with a tracheostomy has been shown to significantly affect carers sleep, emotional wellbeing, relationships and family life. [7 10 17]

A literature review in 2013 highlighted the lack of qualitative research investigating caregivers' views and experiences of looking after a child with a tracheostomy. [7] Since this review, there have been a limited number of studies completed within the UK setting, although these have made a valuable addition to our understanding of the burden of care on these families and their training needs. [8 9] Qualitative research from other countries has also focused on specific experiences, such as decision-making around tracheostomy procedures and risk communication, [12 18 19] transition to home, [20-23] and the perspectives of children and young people themselves. [24]. These studies have mainly focused on the experiences of parents or other informal carers. [25] Transferability of these findings to the UK healthcare setting, however, may be limited and there has been limited research that includes the perspectives of professional HCPs.

We therefore sought to explore the experiences of both parents and health care provider caregivers, to allow valuable comparisons with a focus on the interface with the health and care system across health care and home settings. Through this exploration we aimed to provide insights into care quality improvements and, or measures to improve the experience of caring, and quality of life, for carers.

METHODS

Qualitative semi-structured 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 of England. This centre serves a region that includes urban and remote rural areas and has an above average level of deprivation compared to the rest of England.[26]

Participants and sampling

All potential participants were approached by a clinician from a tertiary care centre with expertise in paediatric tracheostomy and provided information about the study in person, by email, or post. Health professionals were purposively sampled to include variation of accounts in relation to professional roles (nurses, doctors, allied health professionals) and healthcare setting (covering primary, community, secondary and tertiary care) from across the North East of England and with different levels of experience of providing care for children with tracheostomies. Parents with experiences of caring for a child with a tracheostomy were purposively sampled to include diverse accounts in relation to age of child, range of additional care needs, time since the procedure, and from those living across the large geographical region covered by the same tertiary care centre.

Data collection and analysis

Topic guides were developed based on key areas from the extant literature. Parent and HCP topic guides differed in question wording and additional prompts, although key areas covered were the same. These included experiences, training, resources, support and impact of the pandemic with specific prompts around individual and environmental context, the healthcare setting, specific needs of the child(ren) being cared for, emotions, coping, interactions and outcomes. Questions were open-ended with a focus on pursuing opportunities for exploration of participant-led topics and discussion. Data collection and analysis continued iteratively and concurrently and continued until no new themes were evident within the data (data saturation). Although key questions from the topic guides did not change throughout the data collection, some further specific prompts were included, where relevant, to enable comparisons with earlier interviews. All interviews were recorded and transcribed verbatim and field notes were recorded after each interview. Transcripts were anonymised and coded with the help of NVivo QSR International Pty Ltd software version 12, 2018.

Exploratory data analysis was conducted iteratively in line with Braun and Clark's six phase approach to reflexive thematic analysis [27]. This involved: familiarisation with the data, initial coding, generating "patterns of shared meaning" (themes), reviewing and validating themes, defining and naming themes, interpreting and reporting. The coding process was informed, but not restricted, by qualitative evidence on experiences of care providers of children with complex medical needs [28] and key constructs from a theoretical model of the experiences of caregiving, the Informal Caregiving Integrative Model (ICIM). [29] The ICIM was developed based on integration of evidence from work around informal caregiving stress and professional burnout. The processes described within this model were felt to be applicable to understanding the experience and impact of providing care more widely, despite stress and burnout not being a specific focus of our study. This informed our initial coding and theme development; however, the main emphasis of our analysis was placed on inductive coding to allow prominence to the voices of our participants. Initial coding was developed into key themes that described the determinants and mediators of the experience of caregiving in this particular context, as well as the impact this had on families, healthcare providers and children. The themes described in this paper focus on the influences on the experiences of caregiving at the interface with the health and care system from the perspectives of HCPs and parent caregivers. An overall coding frame was developed that allowed comparisons between the data and key themes from within both parent and HCP accounts. Data collection took place during the early stages of the Covid-19 pandemic, which had a substantial impact on the experiences of caregiving at the time of the interviews. This was an important contextual factor that was accounted for during the interpretation of our findings but was not the focus of this analysis and is described in more detail elsewhere.[30]

Interviews and analysis were conducted by a post-doctoral researcher with expertise in qualitative methods, behavioural science and health services research (XX) positioned outside of both the health and social care provision and work context of participants. Analysis and findings were shared with the rest of the research team, who have a range of clinical experience and expertise in tracheostomy care and training as well as qualitative research, to support enrichment of interpretations and for sense-checking and validation. Minor changes were made to improve the focus of the analysis, clarity of the narrative and connections between themes.

Patient and Public Involvement

Carers of children with tracheostomies were consulted informally within clinical settings about their views on the importance of research exploring experiences of caregiving, but were not specifically involved in the design, conduct, reporting or dissemination of the work.

RESULTS

Interviews (n=34) were completed with 17 parents (15 families) and 17 professional health care providers (HCPs). Participant characteristics are summarised in tables 1 and 2. Most parents had children who had a range of complex needs in addition to their tracheostomy and one had recently been decannulated.

Table 1 – Participant characteristics: Parents (n=17)

	Numbers	**Identifiers (Parent)**
Time since tracheostomy at interview		
<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
Child's age at tracheostomy		
<1-6 months	11	P2, P4, P7, P9, P10, P11, P14, P16, P17, P19, P20,
7-12 months	3	P1, P13, P21
>1 years	3	P3, P5, P8
Carer interviewed		
Mother	14	P1, P2, P3, P4, P5, P7, P8, P9, P14, P17, P16, P10, P19, P21
Father	3	P11, P13, P20

Table 2 – Participant characteristics: Professional health care providers (n=17)

Speciality	**Role**	**Numbers**	**Identifiers (Professional health care provider)**
Otorhinolaryngology	Surgeons and specialist nurse	3	HCP1, HCP11, HCP7

Paediatrics	Surgeon/Respiratory clinicians/nurses	4	HCP8, HCP9, HCP10, HCP6
	Allied health professionals, A&E/Intensive care nurses	5	HCP4, HCP12, HCP13, HCP14, HCP17
Community /primary care	Community nurses	2	HCP3, HCP16
	GP	1	HCP15
Other	Secondary care paediatrician	1	HCP2
	Specialist transport services staff	1	HCP5

Interviews (n=34) lasted from 40 to 125 minutes. Accounts from HCPs and parents differed in relation to content and depth of narratives with most HCPs' interviews being shorter. This reflected both the more limited experiences of caring for children with tracheostomies by some of the HCPs interviewed, but also that caregiving was experienced and described as part of their professional roles. For parents, on the other hand, experiences of caregiving were inextricably intertwined with their everyday lives and identities as parents. This involved the sharing of more personal accounts and additional thematic complexity.

Figure 1 illustrates our coding framework and proposed links between the themes identified. Themes centre around the wider context, determinants and mediators of caregiving experiences and related outcomes. These reflect a range of carer demands and resources associated with: lived or professional context, individual clinical and support needs of the child(ren) being cared for, and the social environment and clinical settings in which caregiving is situated. Participant accounts described how these are influenced, and influence, interactions within and across health and social care settings. Key themes and how they interrelate are described in more depth below and evidenced with verbatim participant quotes qualified with anonymous identifiers.

Insert figure 1 – Influences on the experiences of caregiving

Determinants

Individual "back stories"

Our theme of individual "back stories" came from the words of one of our participants who used this term to refer to important aspects of their lived context and experience that impacted on their

caregiving. This theme also maps to the caregiver demands and resources element of the ICIM model.[29]

As to be expected, key aspects of the "back stories" reported by participants that influenced the experience of caregiving differed between parent caregivers and HCPs. These determinants impacted on various aspects of their caregiving experience and included: perceived ability, capacity and confidence in being able to provide high quality care, perceived and actual burden of care, beliefs about the caregiving role, as well as interactions with and within the healthcare setting.

For parents, ability and capacity to deal with the demands and burden of caregiving included: their own existing physical and emotional health; family background and circumstances; complexity of their child's care needs; and previous experiences within the health care setting. The following quote illustrates the processes in figure 1 from the perspective of one single parent who described how key aspects of her own "backstory" had shaped her experiences of caregiving and her perceived ability to deal with the learning requirements associated with providing tracheostomy care for her child. It also highlights how interactions within the health care setting were integral to this experience. In this example, she recalls how one interaction had exacerbated the burden of adapting to the demands associated with becoming the sole caregiver of a child requiring 24 hour care, whilst dealing with the associated biographical disruption to her own life.

> *"Some of them listened to your back story ... I probably am a bit slower than other people, do you know? there's no shame in that like but, some of them I just think were just like, a bit rude to me. …I want to add I'm at me discharge meeting at me lowest ever ebb, and I'm so down [emotionally] and I just remember thinking you just don't get it do you? You just really don't get it like, this is what I'm gonna have to go home to, this is gonna be twenty-four seven to me. The carers they don't get it neither because they clock off and go home." (Parent 5)*

HCP narratives were primarily grounded within their professional rather than personal experiences, and their "back stories" were mainly related to: HCP role and work setting; professional competence and confidence; level and frequency of caring for patients with tracheostomies; and knowledge and training in tracheostomy care. Depending on their professional role and work setting, commonly mentioned challenges included limited opportunities to gain experience of caring for tracheostomised children due to limited frequency of contact, as well as the importance of access to training and updates. One of the HCPs described how the learning from an initial training day was difficult to embed due to infrequent exposure, which was more of an issue for those not working within specialist tertiary care paediatric wards where dealing with children with tracheostomies was more common.

"So, like, you only get competent the more you see the patients, don't you? .. you go on the trachie study day and then you're expected to see so many patients to get signed off in order to be classed as competent for your trachies, but in this setting [emergency care], they're almost quite few and far between and then we'll have like little flurries, so you tend to get quite a lot of trachies through and then some where you feel like you don't see a trachie for ages, so I think if it's been a little while and say you get a pre-alert for a trachie venting in resuss [Resuscitation], you think "oh God, it's been a little while", and you sometimes run through that thing in your head where you're being like "what am I doing?" So, I think that's probably the biggest challenge" (HCP 14)

Caregiving settings

Although individual level determinants on the experiences of caregiving were distinctly different between HCPs and parents, there were some key influences on the experiences of caregiving that were shared, albeit with different impacts on both groups. There are key structures and processes within health and social care settings in relation to HCP and carer training and support, including the sign off of required competencies, hospital discharge, respite care packages, and ongoing support that form a key part of the experiences of caring. These processes are subject to organisational level influences, as well as those originating from the wider socio-political, environmental and wider healthcare provision context. Furthermore, the majority of caregiving is centred and provided within the family home. Where the family lived was reported to have an impact on the health and care support available. Variation in provision and capacity across local authorities, who in the UK are responsible for providing funding and availability of respite care support, as well as differences in the capacity and management of local community nursing teams commissioned by secondary care trusts. This presented different experiences for parents from different areas and with different care needs for their child(ren), as well as challenges to the HCPs supporting them. Distance of the family home from the tertiary care hospital, in some cases, could also influence the experience of parent caregivers due to the impact travel time and costs, as well as variable access to healthcare providers with expertise in tracheostomy care in an emergency. One HCP suggested that standardised minimum care quality standards would help to address the "lottery" of system variability and its impact on families.

"I think it can be a bit of a, a lottery as I say to, you know, sometimes who shouts the loudest gets the most. Maybe it's where they live, or, you know, kind of all those little things that might affect funding…. things are very different from area to area and, you know, should we have those basic sort of quality standards, , … should there be a minimum requirement for, the input in the care that these children and families receive, … it can be so hit and miss." (HCP 3)

Examples were provided by some HCP participants highlighting recent improvements in practices to address variability, particularly around training. Box 1 includes example quotes that help to illustrate accounts of the challenges and sub-themes associated with the variability in access to support and care. The impact associated with changes to these systems and processes that were specifically as a result of the Covid-19 pandemic and the need for infection control, such as restrictions on visitors and PPE requirements is described in more detail elsewhere. [30]

Box 1 –Variability in care and services

Sub-theme	***Example quotes***
Financial support packages and respite care	*"it's very variable about how much care package you get, depending on where you live. It's not standardised… if you live in [place X], you might get a bigger financial package and more hours [respite care support] than if you lived in [place Y] and it just doesn't seem to be any rhyme nor reason towards that, it's just dependent how much money and how many children who have got tracheostomies with special needs in the area" (HCP 7)*
Quality of care	*"everything is always a constant battle. . The same with even getting an OT out. At the moment we've got two fantastic OT's who are really on the ball, which is great, but they don't tend to stay more than a year. We had...there's such a fast turnover in the system of- all specialists. It's the constant change that can be an issue a lot of the time." (Parent 9)* *"in hospital you become so dependent and reliant on people around you.. and suddenly .. It was just like, hospital into home with carers who wouldn't have a clue how to care for a goldfish.. Let alone a child with a trachie" (Parent 5)*
Access	*"me and my husband both feel that we always say that we're really lucky to live where we live and to have the [name] hospital as our local hospital … we've got access to such um you know specialist in our area, so we do feel very, very lucky .., we've always said that the level of care that we've got there has been so high, that we're just lucky that we live close-by" (Parent 7)*
Training provision	*"We have quite a junior staff base. We get quite a lot of newly qualifieds in, and I think trachies are the one thing that I feel like everyone is pretty scared of when you haven't got experience of them. And so I think until you get some supported learning and some supported practice with the trachies, they seem like a bit of an intimidating thing, which you can imagine [pause] for parents must be really challenging when you're coming into an environment where – not that the parents would always know that, but I think as a department we're quite good at now trying to get people on their trachie study day quite quickly." (HCP 14)*
Staffing, skills and capacity	*"It's very much kind of potluck, but when you're a junior nurse, you may end up being more competent quicker than somebody else that you*

	started with on the same week, just because the, the mentor that you're working with, um, you just so happen to be getting more tracheostomy patients than somebody else. So, it's just… luck of how often you get these patients, but how quickly you build up your skills and confidence in looking after these patients." (HCP 12)

Interactions: Navigating and negotiating the shared care space

Children with tracheostomies often have a range of other complex care needs and require involvement from a number of different secondary and tertiary care specialities, community care, social care (including independent care agencies) as well as general local hospitals and primary care practitioners. For children of school age, training in tracheostomy care is also provided to staff in nursery and school settings. This involves the navigation of complex health and social care systems and negotiation around the shared care space. The processes and structures described in the section above are primarily aimed at enabling transfer of responsibility of day-to-day medical care of children with tracheostomies to their families and other carers. For many the transfer of responsibility seemed to have been an accepted and taken for granted assumption, rather than an explicitly negotiated shared agreement. Key sub-themes relating to the negotiation required within this complex shared care and cross-organisational space included communication, relationships, trust, empowerment and other power dynamics.

There was recognition within HCP and parent accounts of the importance and value of the expertise of parents in relation to the care of their child and the complexities and challenges around the sharing of medical expertise and shifting of responsibilities over time. This could also at times be incongruent with expectations and traditional norms around parenting roles and responsibilities.

> *"when we were doing the training, the nurse – I remember the nurses like quite vividly saying "you're going to be the experts at this soon", and [father's name] and I laughing, because I thought they were joking… but they were right" (Parent 4)*

From HCP perspectives, an emphasis was placed on empowering parents to be able to care for their child on their own, whilst ensuring they were able to meet the required training competencies in tracheostomy care.

> *"we always try to sort of empower the parents to take on the activities, once they feel able to do that rather than just being a spectator and, you know, the nurse coming in and washing and dressing the child and giving them medication, and maybe the play team come in to play*

with the child, it's like, well you're the mum and you're the dad, you would've been doing all of this. So it's very much about sort of empowering and sort of acknowledging their role, they are still the mummy and the daddy, and they need to look after this child, and helping them do that, but, so it's a really kind of emotional time. (HCP 13)

Shared care and responsibility could, nevertheless, at times involve an unspoken and complex negotiation of power and trust that needed to be navigated in varying ways across different professionals, hospital departments and healthcare settings.

"I was asking them [the nurses] at first but then .. as time went by I just thought right I'll bath her (baby) I'll do it all myself and then I'll give her a trachie change. And then they would come over and they're like 'oh has she had her trachie changed'? then that would knock me because I'd think 'oh god should...did they need to know that I was doing that'? ... They weren't saying I was doing anything wrong, do you know what I mean? But it, do you know when you start to doubt yourself thinking 'god should I have passed that by them or...'?" (Parent 14)

"The parent is very much the expert and I think we have to be guided by that quite a lot on here, which can be maybe a bit of a challenging thing to get your head around initially, because you feel like you're the one who's supposed to be like managing, .. I think I always adopted the approach of, like, just be really transparent about it. Like talk to the parents about what's their child's normal. (HCP 14)

All parents over time seemed to recognise the importance of their role and their contribution their expertise in caring for their child brought to their overall care and their need to advocate for their child.

" it's so important for a doctor in general to listen to parents and the way I try to describe it to doctors, is that they're the expert in medical needs and how the body works and what things need to be done to keep the body working well.. but I'm the expert in [Child name]" (Parent 20).

Lack of trust and previous negative experiences of not being listened to, or their knowledge not being acknowledged, meant that many parents felt strongly that they needed to advocate for their child to ensure they received the quality care required.

"[child's name] cannot speak out, so I have to be her advocate to make sure that things go well for her." (Parent 8)

Being listened to and valued was seen as positive by parents. For one parent, who has been involved in a training event for HCPs, and for HCPs, there was acknowledgement of the value of sharing experiences (see box 2).

Box 2 – Sharing parent experiences

Value of shared experiences
"I tend to talk them through .. just, kind of, the curveballs we're thrown and how as a family we deal with that and how it's important that we're listened to whatever ward we end up on, because obviously I've talked about how ward [paediatric respiratory] know [child name] inside out, but that's not the only bit of the hospital. We have to go through the A&E where the nurses aren't all trachie trained and just kind of explain our experience of that, because there has been some hiccups" (Parent 4)
" I honestly thought it [parent talk] was possibly the best thing of the study day because it – it's that – you forget – you don't forget but it's that –this child is that family's most precious thing and they're a really complex child and this is, this is what they have to contend with every day and it takes a lot for them to give that over to you when they're concerned, especially if something has happened which they haven't… so it was something along the lines of the child – somebody was trying to put them on their circuit, on their wet circuit, but ended up trying to put an oxygen port on their blow off... and obviously the parent was like "no, no, don't do that", that's what this family go and talk about and the learning that you get from somebody who's gone through something like that because it seems practical sticks with you a little bit longer. It also probably scares you a little bit, but I think that's a good thing. (HCP 14)

Parents who had been caring for their child at home were also routinely relied upon to provide tracheostomy care within healthcare settings. Parents' narratives included examples of negative experiences that had resulted in a lack of trust and a need to check that the HCP looking after their child was competent in tracheostomy care.

> *I've noticed when parents know that you're tracheostomy trained and experienced then they're a little bit more relaxed and are happy to kind of leave.. um they can then go and get a little bit of respite as such." (HCP 5)*

This additional burden and responsibility tended to be an accepted and expected part of caring for a child with a tracheostomy and was subject to variation across different care settings. Box 3 includes quotes that exemplify how reliance on the expertise of parents can be influenced by a lack of standardised training, infrequent exposure and the need for different care routines.

BOX 3 – Expert parents

	"And the parents are appropriately trained… but, healthcare professionals aren't being trained to the (tertiary care hospital name) training standards. I think that we're not being offered training days, we're not being offered training-up dates… obviously there'll be new student nurses qualifying who may be looking after a child on a ward with a trachie. We're, often relying on parents, because parents tend to do self-care when the kids come in. So they'll do the trachie changes, secretions, and if the trachie blocks the parent is there to change the trachie. .. The nurses know how to use the machines…but my understanding is that often it's the parents who, erm, who, who get things set up because that's part of their routine and they, they keep going in hospital. They don't change that routine. .. The parents are absolutely the experts. (HCP 2)
	"And then, she started going downhill, down...they [hospital staff] didn't actually know how to change the settings on the ventilator. They didn't know how to up her pressures. I did, luckily, cos I watch when I shouldn't.. So, I had to show them how to do it and then they upped her pressures and then they transferred her to the (hospital name).. (Parent 16)
	"Over the years you see adults occasionally but honestly, this is so rare that, you know, there's no... you know, you have got loads of experience. I've been a GP for thirty years and they, you know...er, you know, I've seen individuals and but often adults will be um experts in their own trachies.. the mum of this little boy [with a tracheostomy] would be the expert if, you know... I would just have to ask her the questions. (HCP 15)
	I think, erm, it's quite interesting though, that on, on occasions where I've phoned an ambulance for a child before, erm, ambulance crews aren't, like, trained to care for children or people with tracheostomies, so then they sort of heavily rely on the parent or, , you know, us in the first instance to kind of actually guide them through, , what we need them to do, if you like. (HCP 3)

The importance of good communication and building relationships that support trust and enabling a collaborative approach to shared care was highlighted by many of the HCPs and parents alike. See box 4.

Box 4– Relationships, communication trust and continuity of care

Continuity of care	*"I think having those relationships, it's really important, especially, as I say, for children like [child's name] , that they have time to get to know the staff and the staff, we were going into A&E once … and I always remember the girl was called (name) I think she's a Ward Sister there now, and she just went straight away, 'I'll get you into a side room because I know [child's name] doesn't like lots of strangers' and as we walked into the room she turned the lights out and she went, 'She doesn't like bright light neither, does she?', and I was like, 'Thank God we've got somebody here who understands and remembers, they know and could remember visits in the past when I'd said, 'Can we lower the lights, because she struggles in a really bright light?'…, that made a massive impact for us and our visit on that day…and it's that, it's that kind of, it might seem a small thing but it's huge, it's huge to parents to know,.. (Parent 8)*

	'I'm going to be seeing So and So, I can ask them anything that, you know, they'll not think I'm stupid if I ask what I consider to be a daft question'… as parents, if it's something new you need to and if it's got to be done in a particular way you need somebody who has got that relationship, can go, 'Hang on a minute, no, that's, that's not right, don't do it like that… because this could happen'… but if you've got somebody who you've got a relationship with,…who you trust .. then you can, you can have very honest conversations and sometimes that's what needs to happen from both sides. (Parent 8)
Communication	*"I think communication is probably the key to everything. ..communication between professionals, between professionals and the family, and in a way that everybody understands." (HCP 13)*

In the region from which our interviewees were based, a paediatric tracheostomy specialist nurse had been appointed to help provide oversight over family and HCP training, care standards, support with communication and coordination of care needs across health and care settings, and providing continuity of care and a key point of contact within a complex care system. This role was valued and was also seen to be important in avoiding over-reliance on parents as communication conduits between different elements of the healthcare system (See box 5).

Box 5 – Importance and value of specialist tracheostomy nurse role

Value of specialist tracheostomy nurse role
" you need to have more (specialist nurse role) because…she's the only trachie expert in the hospital... So, I think, you know, if you had other, possibly another two people who were trained, ready to step into that role, erm, and also to be there so parents get to know them before a change happens, erm, so that you can build that relationship… if you just have a child who was coming in who didn't have any additional needs, was poorly, was getting a trachie, and you hadn't been in the hospital system before, it, it can overwhelm you. So, I think … the most productive relationships are the ones that are based on trust and familiarity, so you know the person when you're coming in, that's a big thing and it's a big thing for the children as well, to have somebody in that continuation. Not to be chopping and changing all the time." (Parent 8)
" once they're discharged, we sail along and if things are going smoothly, we probably don't need to have that communication very much with the hospital. The parents tend to tell you what's happening. So they're... you know, we're going back in for a study or we're going back in for a review or the trachie needs upsizing. So that... we tend to just get that all from the parents. Um but I must say, the last few months, [name], the specialist nurse, has been … giving us information that we would never have normally had". (HCP 16)

Mediators

The examples provided in the sections above also provide reference to some key mediators of the experiences and outcomes of caregiving for both parent and professional caregivers, such as coping ability and styles; self-efficacy; availability of and, or access to physical resources such as equipment, funding, training and respite care; and social support.

Parents described how ongoing communication and relationships with HCPs become an integral part of everyday life. Most children, particularly those with other complex medical needs, are seen by a wide range of HCPs. This was often associated with practical difficulties in managing multiple appointments and perspectives. The need for respite care, either from extended family or other social care providers was, however, a key challenge for families and played a key role in parents' experiences of caregiving. Access to and perceived value of online forums and support groups was variable, however, when available, social and informational support from other families with similar experiences was reported to have had a range of positive impacts, including health outcomes for some children as well as emotional and physical health of the parents.

Tracheostomy carer training ensures parents have sufficient knowledge and met standard core competencies for meeting the physical care needs of tracheostomy care, however, perceived preparedness for other aspects of care and support with the burden of care was more varied. For example, psychological support was unavailable to many parents, or was only available through other routes such as through other hospital departments, including the special care baby units. Support with accessing and dealing with the management of respite care arrangements via local authority care plans, or the organisation of multiple multi-disciplinary specialities appointments and follow-up plans was also reported to be inconsistent (See Box 6).

Box 6 – Mechanisms of support for parents

Sub-theme	Example quotes
HCP support	*"I had to push to be, escalated to the (name) hospital and [get the] support that I've had. .. but (consultant name) and (name) and the two of them that are just, the most amazing support that was offered to me…Even after, after her trachie do you know what I mean these two people, well not (name), cos I haven't seen (name) for a while but (consultant name) He understands and I think it was having someone believe in you and understand you made it easier to then look after my daughter. Cos I just didn't feel like it was all going wrong and I was getting it wrong and like other people knew better than me.." (Parent 5)* *"one of the problems you can have with a tracheostomy is over grannulation. unfortunately normally community nursing teams are meant to deal with that but our community nursing team don't [offer specific treatment] … [specialist nurse] actually came out to our home and did the treatment at home, which was fantastic" (Parent 19)*

	"they do listen.. the individual teams at [hospital name] seem to do that quite well and work together...what the problem is is that once you come outside of that one hospital, it doesn't come together as well.. that working together and taking account of all the, all the other needs together, isn't there as much" (Parent 20)
Respite care	*"we had like an MDT in the hospital and it was agreed that we'd need a carer to come and help with (child's name) 's care at home because obviously we've got another little one as well. It was agreed that [child's name] could access respite facilities, um and this was all before the [covid-19] lockdown. So when we did get home, all of that discussion and all of those plans were put on hold because we couldn't get any carers and it was due to the training, we couldn't get anybody to the house, we couldn't access respite" (Parent 3)* *"it's difficult. Erm, which is probably why we've managed to stick with one carer. We've had a few others come and go. Erm, that were kind of...you know...like [carer name]'s relief workers really and its awkward for everyone all round, isn't it really. Having someone else in your home, but you tend to just get on with it, and like I say, if you click with that person then it-it works out…Yeah, she's just like another family member now. [laughter]" (Parent 9)* *"if we don't have [respite] care, if we've been up all night... meeting [child's] care needs, how are we able to meet their care needs the next day? Me and the wife have both had treatment from the doctors for exhaustion.. we've both got one or two health conditions, since we've been caring for [child]. Before, you know, I was fairly healthy.. I've got to lift him everywhere ..because of that I've er injured my neck and I've got constant pins and needles down the left hand side of my body" (Parent 20)*
Online groups and support from other parents	*"I think as time's gone on it's all the practical things, I've found that Facebook [tracheostomy] support group really, really useful and there's things that I've learnt from there that I wish somebody would have told me early on."* (Parent 7) *"Most of them seem to end up on social media and go on to some scary Facebook page. So we try and avoid them to do that. We try and sort of say, look, at this one first, some more factual information and then some of them will just naturally then head towards Facebook groups for support." (HCP 8)*
Other Social support	*"It depends on the families and it depends on the support systems they've got in place at home because I think if they've got family that are good and support them and happy to help out in any way, then... but I must admit, the last six months have been hard for families, haven't they? Covid, not being able to get anyone else to, to give them a break. (HCP 16)*
Psychological support	*"we don't have a psychologist on our ward for parents, which absolutely makes no sense when there's a psychologist on most wards for, not minimal, but to our, our standard, minimal things. So it's the parents that are dealing with the child that's going to die and they have no psychological support, which is just ludicrous. We don't understand it. Apparently, there's no funding for it and for us to have one. So I feel like, if we had a psychologist, they would definitely feel... it would be nice to have someone who wasn't..., that's always around them and*

	to just talk through the situation, not from a medical point of view, just, you know, like first from a psychological point of view from the parents... (HCP 17) *" I had to arrange it [counselling] myself. I went for an assessment with the perinatal mental health team in [name] hospital and they wanted us to, seek some support at the [name)] hospital from the psychologist on the trache team, but I wanted something that was completely separate to [child name]. I don't want… like, what I'm talking about to, to be linked with [child name]. For me the [name] hospital has got a lot of bad memories, so I didn't want the memory travelling to the [name] hospital for whatever support….. so I've gone private with it." (Parent 17)*

For HCPs, a key mediator was the support they received from their immediate work colleagues as well as wider multi-disciplinary teams. This played a key role across all settings in their experience of, and confidence in, providing high quality care to children with tracheostomies. Narratives suggested that communication and relationships between health professionals is critical in supporting shared care, burden, responsibility and decision-making and is stronger within, rather than between, health and social care setting boundaries. The specialist nurse role mentioned above was seen to provide a valuable addition to helping improve access to standardised information and training and supporting communication between different care teams. Professional networks were also seen to offer reassurance and provision of up-to-date knowledge. Established clinical pathways, protocols and processes around all key stages of caregiving (e.g. from assessment, decision to tracheostomise, training parents, discharge and follow-up) were also important mechanisms for supporting HCP roles and key to facilitating self-efficacy. Box 7 provides examples of how different types of support can impact on HCPs experiences.

Box 7 – Mechanisms of support for HCPs

Sub-theme	***Example quote***
Team working	*"if we have difficulties at a weekend and I was really struggling with a problem I'm sure one of them [other members of the team off duty] wouldn't be concerned if I gave them a call and asked for advice, or even you know to come in and give me a hand if there was a particular issue. So, we have a good support network." (HCP 1)* *"think some of the challenges will be in… in terms of making that decision, and making sure that you've, involved the parents fully in the discussion. you'll… kind of, go through the different options that might be available, , you've explored those options, you've discussed with, like, the relevant teams. You know, whichever teams… other teams might be involved. So as a collective, I suppose you can come to, an understanding and a decision*

	about what's in the best interests what's needed for the child at that time." (HCP 10)
Professional Networks	*"you can gain an insight in terms of what's going on, , nationally, I suppose, through discussions that you might have with peers, or at, conferences, or other events that you might attend, … and there's an opportunity to attend, study days"* (HCP 10)
Clinical pathways and protocols	*"having a protocol has really helped, so everyone does the tracheostomies in exactly the same way, in a very stepwise manner. … that really helped me in terms of my understanding and learning of the steps, is that I always had that structured method of doing things.. it's not sort of a national protocol, but everyone works along the same sort of guidelines."* (HCP 9)
Training and exposure	*"so there's the trachee study day, which is delivered or arranged by the airway specialist nurse, so there's that training. but kind of training as an OT [occupational therapist] sort of from university, you, you wouldn't get any specialist training. I think most of it is kind of learning on the job, and any in house training that you, you can be party of and, you know, the specialist nurses are very good, and are very willing to kind of go through things, and, you know, should you need to know like anything more." (HCP 13)* *"I think the trainees are getting more exposure to more complex paediatric ENT procedures than they used to. I think that is certainly something that is good and compared to it was say ten years ago". (HCP 11)*

Key challenges described, however, included variable capacity of teams and differences in expertise and experience across departments and even in some cases, shift patterns. Some HCPs found dealing with the emotions of parents and children more challenging than others, this seemed to be partly due to individuals but also to expectations relating to their professional roles. The following quote explains how this can be affected by a range of factors, including the needs and age of the child.

> *"I found that a lot harder because it, not only were you dealing with the parents' anxiety and fear, but hers as well, um, because she was that much older, she'd got all of this experience of not needing a tracheostomy. So she was really fearful, she was really anxious. Every time we would come near her, I mean I can't even begin to imagine what the, the feeling of having a tracheostomy suctioned, you know, it must feel horrendous, so, and you could see it on her face. She, she was just terrified the whole time that we were near her. .. a few of us went down to see on the ward afterwards and she'd totally got used to having that tracheostomy but I think, for me, it was just seeing that fear in her face " (HCP 12)*

Outcomes: Individual and general

As illustrated in Figure 1 and described above, reported experiences of caregiving includes wide-ranging impacts on the caregiver, the child, and in some case also immediate and extended family, including siblings, grandparents, etc. The burden of care on parents had far-reaching impact on all aspects of their and their families' lives, including their psychological and physical health, quality of life, and employment opportunities, as well as the cultural and societal norms and expectations associated with parenthood. These experiences in turn can influence their perceived ability and capacity to cope, which can then reinforce and further impact negative effects of stress on health and wellbeing and the capacity and ability to provide quality care.

Although a number of challenges were described by HCPs, there was little perceived impact of providing care for children with tracheostomies, due mainly to this being an expected part of their professional roles. Where emotional impact was reported, this was not seen to be specific to caregiving for children with tracheostomies and often described as "part of the job". Although impact was not a major theme in the HCP accounts, when it was mentioned, this related mainly to confidence, perceived quality of care provided and job satisfaction.

DISCUSSION

In line with theoretical frameworks for understanding the impact of informal caregiving [29], our findings highlight key determinants (family capacity and ability; health provider capacity and ability; system factors; and factors relating to the interface with the health and care system) and mediators (coping and appraisal; self-efficacy; physical resources; and social, team and professional support) that influence how people deal with caregiving and the impact this has. For parents, access to care packages and respite care at home are key influences on their experience and quality of life. For HCPs, the importance of multidisciplinary team and colleague support, established clinical pathways and processes, and access to training and updates were most important. The related impacts of caregiving (such as psychological and physical health and quality of life of parents and their families, and confidence and perceived quality of care) can in turn influence re-appraisal of the situation, self-efficacy and coping resources. This is in line with established evidence and theory on stress and coping, whereby, with any response to a potential threat or stressor, there is an ongoing process of reappraisal of an individual's initial or primary appraisal of the threat as well as the resources and coping strategies at their disposal to respond to it. [31]

Our findings map closely to the constructs included within the Informal Caregiving Integrative Model (ICIM) [29] which informed our initial coding framework. Although this model was developed to explain informal caregiver burnout, which was not a key focus of our study and did not appear in the narratives of HCPs, we feel that the processes and constructs within it were able to be more widely applied to the general psychological and emotion impact of caregiving in this context. Our analytic approach was therefore theoretically informed but allowed flexibility and ensured that emergent themes reflecting the voices of our participants were incorporated into our final coding framework and findings.

A key theme threaded throughout our findings was the lack of standardisation of many aspects of health and care settings in which caregiving experiences were situated and the ad-hoc nature of some key mediators. Examples included: geographical variation in access to different support teams, care packages and respite care; differences in access to regular training and updates; variation in health provider expertise and experiences across roles, settings and even shift patterns, which can be exacerbated in healthcare settings with limited frequency of contact with children with tracheostomies. Other wider policy and organisational influences included resource and funding constraints, existing relationships and communication between primary, community, secondary, tertiary and social care. As a consequence of the timing of data collection, the Covid-19 pandemic, was also a key theme and this has been described elsewhere. [30]

Our findings concur with previous work highlighting the significant burden placed on parents who care for children with complex medical needs, and in particular children with tracheostomies. [7 8 10 17] Negative impacts on quality of life, physical and mental health and family function have previously been reported in families with children who rely on medical technologies [15 21] and tracheostomies more specifically [7 20]. This includes effects on sleep, relationships, social life and ability to work [10]. Our findings also complement qualitative research from other countries focused on specific experiences, such as decision-making around tracheostomy procedures and risk communication, [12 18 19] transition to home, [20-23] home care, [32] social support, [33] and health care seeking. [34] These studies have focused mainly on the experiences of informal caregivers and on intensive care settings. [25] Our study included a range of perspectives from families with children of different ages, care needs and time since tracheostomy, as well as the inclusion of perspectives of a range of HCPs, and a focus on the interaction within the shared care spaces across health and social care and home settings.

Findings from UK based studies have previously identified a need for regular revision of skills and information around paediatric tracheostomy clinical care for informal carers [9 10] and HCPs [13]. A need for improved tracheostomy education among paediatric HCPs to help improve knowledge,

confidence, and skills has also been identified in the US.[35 36] Our findings suggest that standardised and regular training provision and availability, in particular for HCPs who do not have consistent exposure to providing paediatric tracheostomy care still remains an issue.

A recent qualitative phenomenological study focusing on the facilitators and barriers to the tracheostomy decision-making (TDM) process[18] highlighted the importance of communication and team working. Our findings suggest that this is an important aspect of the caregiving experience for families and HCPs across the entire tracheostomy care "journey". We also highlight the challenges associated with clinical care responsibilities being transferred to parents and the need to acknowledge and include parents as experts. Our findings concur with those from a qualitative study on the experiences of parents of children with rare diseases [37], other complex health conditions [38-40] or who require complex medical care at home [15], whereby key challenges for parents were navigating the healthcare system and the added burden of the additional role of care co-ordinator. Work in the US and Canada has shown that the use of patient navigators [41] or family centred care coordination [42] can be helpful in supporting patients and their caregivers in navigating the healthcare system to improve access and integration of care and improving quality of life.

Findings from a study exploring the mechanisms through which an interprofessional team approach can improve the management of patients with a tracheostomy found that communication and the use of standardised practice protocols were important. [14] We are not aware of any research that includes family carers as experts within the MDT team and Baumbusch, et al. [37] highlight that parents' roles as expert caregivers are rarely acknowledged by HCPs. In contrast, our findings suggest that this was a fairly widely accepted narrative across our HCP sample. For example, there was a reported acknowledgment of reliance on the expertise of the parents in the tracheostomy care of their child across a range of healthcare situations and settings, particularly when HCP expertise or knowledge of individual children's care needs are lacking. How to negotiate this complex power dynamic was not straightforward and is not often explicitly addressed. Kirk [43] proposes that expectations of parental involvement, feelings of obligation and a lack of community resources can act as barriers in negotiation of care roles and that it is important that changes in power dynamics and parent-professional relationships are based on partnership rather than conflict. Our findings highlight how this process is also likely to be closely intertwined with parents' navigating their own biographical disruption as a result of their child's needs and what it means to be a parent, particularly when expectations and responsibilities normally associated with parenting is temporarily taken over by HCPs, as also described in previous work with parents of children with mental health conditions.[44]

The importance of standardisation of care and training to help improve care quality has been previously highlighted.[45] Initiatives such as the Global Tracheostomy Collaborative (GTC), [46] and work looking at the potential of virtual and online training as a result of the Covid-19 pandemic [47] may help address some of these issues in this setting. In England, the multi-disciplinary National Tracheostomy Safety Project has developed a standardised universal approach to improve the management of tracheostomy and laryngectomy critical incidents. [48 49] However, there are currently no paediatric tracheostomy specific service specifications, which are clearly defined standards of care expected from organisations funding by NHS England to provide specialised care for certain specialist conditions or interventions. This means that the levels of care and support are only defined on a local level. We would advocate the development of a paediatric tracheostomy service specification, including extensive multidisciplinary support. Children with tracheostomies often have a range of other complex medical needs, so it is important that the challenges of families in navigating the complexities of shared care arrangements, appointments and support across hospital departments and different health and care organisations are taken into consideration. Our findings suggest that a key area to be addressed for families is accessing funding support, care packages and respite care across different local authority areas. This does not seem to be specific to the UK and has been identified as an issue elsewhere. [50] In addition, supporting access to formal psychological support for families, and wider social support more generally, may also help mediate the consequences associated with burden of care. [51] Supporting the emotional needs of parents and children was also one of the areas that HCPs found challenging in our interviews. Emotional support has also been identified as one of the key areas carers feel needed to be addressed in tracheostomy care training.[9]

The interviewees in our study were recruited from a region covered by a tertiary care centre benefitting from a fairly recently implemented paediatric tracheostomy specialist nurse role supporting HCPs and families. This type of role may help address challenges associated with some important mediators of the caregiving experience and quality of care identified in our study, such as the availability of standardised clinical pathways, processes and guidance, as well as relationships, teamwork and communication across families, health, care and educational organisations supporting children with tracheostomies. Such roles may also be beneficial for developing trust and providing a key point of contact and supporting continuity of care, which has also been highlighted as an important issue for parents caring for children with other complex chronic health conditions. [38 40]

Further research would be required to assess whether national standards of care, or the expansion of novel specialist nurse roles, or changes to training provision may help to improve quality of care. Multiple measurable outcomes could be used, such as reducing the significant healthcare utilisation

and cost burden associated with hospital readmissions in children with tracheostomies [2] or outcomes such as morbidity, mortality, quality of life for children and families.

Strengths and limitations

Despite clear evidence of open and honest accounts from all participants, it is likely that health care providers may have felt sensitive about disclosures that could have been linked to the provision of care or professional practice perceived to be sub-standard. This may have been minimised by the researcher (NH) being positioned outside of both the health and social care provision and work context of participants, however, it is possible that awareness of the involvement of other clinical members of the research team may have influenced participants' narratives. Coding and analysis were completed mainly by NH with reconciliation of inductive and deductive findings involving thoughtful engagement with the analytic process and the data. In line with reflexive thematic analysis[27], it is recognised that the researcher's expertise and behavioural science background will have played an active role in interpretation, coding and knowledge production. Having not previously provided care to a child with a tracheostomy or worked clinically within the healthcare setting allowed a "fresh" perspective not influenced by prior knowledge of the caregiver setting and environmental context. At the same time, this may have limited understanding of the experiences being described. Consultation with JP, who has clinical and setting insight, and NR, who has expertise in qualitative data analysis and patient and health professional experiences of health care, provided the opportunity to sense-check ideas and enrich interpretations of the data, which were then further contextualised by the rest of the clinical research team.

Due to the demands on caregivers' time, interviews were chosen for pragmatic concerns to allow more flexibility to fit in with individual availability. Interactions within focus groups may have provided additional understanding around shared experiences than our individual interviews were able to.

As data collection took place during the pandemic restrictions, all interviews were completed over the phone or online which may have influenced participation and engagement. Only three of the parents who agreed to be interviewed were fathers. This is likely to be reflective of the tendency of responsibility for care to be gendered. [52] Although training in tracheostomy care is required by all parents, our findings reflect those of Harden [44] that even in dual-parent families, the mother tended to generally be the primary carer and was usually, but not always, the main point of contact with health and care services. Further research around the impact of caregiving in this setting on parenting roles, including consequences on employment and financial security, identity and biographical disruption may be valuable.

Inequities associated with respite care and associated funding and resources were important themes throughout the interviews. HCPs included were from health care settings and professionals and informal care givers from social care and education settings were not interviewed. These are likely to have different experiences and needs. Exploring these different perspectives may provide additional insight and be a valuable avenue for further research. Other significant and crucial aspects of parents' experiences of caregiving evident in our interviews were not covered in-depth within this paper as they were outwith the main aims of the analysis but would also benefit from future attention. These include the consequences on identities, biographical disruption, and parenting roles.

Our study includes experiences of caring for children with a wide range of complex care needs that have a tracheostomy. The complexity of their care needs was a key factor in experiences of caregiving and although we were confident that no new themes were emerging from our final interviews, our findings may not be representative of all carers' experiences. Furthermore, our study was completed in a region in England served by one tertiary care centre and may not be fully transferable to other regions.

CONCLUSION

Our findings highlight some theoretically informed issues specific to caregivers of children with tracheostomies that are also likely be of relevance to carers of children with other complex medical issues. Integration of perspectives from both informal carers (parents) as well as formal HCPs can help to understand how to support system level changes to improve the experience of caregiving by improving communication and relationships and reducing the burden and potential psychological and physical impact on informal caregivers. We advocate the development of a paediatric tracheostomy service specification, including extensive multidisciplinary support that accounts for identified key priorities, including recognition of the involvement and expertise of parents, training and ongoing education needs of health care providers and families, increasing use of paediatric tracheostomy specialist nurse roles, and addressing the emotional and psychological support needs of caregivers.

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Ethics approvals

This study involves human participants and was approved by the HRA Ethics Committee reference 20/WM/0025. Participants gave informed consent to participate in the study before taking part.

Author contributions

JP, NR, MB, DH, AJS and SP all made substantial contributions to the conception and design of the work. NH and JP were responsible for data collection, analysis, interpretation of data and leading on drafting the paper, with contributions from NR, DH, MB, AJS and SP around interpretation and revising the work critically for important intellectual content. JP acts as guarantor and accepts full responsibility for the finished work and the conduct of the study, had access to the data, and controlled the decision to publish.

Competing interests

The authors have no competing interests to declare.

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Data sharing

Data is not freely available for sharing to protect anonymity of study participants. The authors will consider any reasonable request for data sharing where appropriate.

REFERENCES

1. Powell J, Buckley HL, Agbeko RS, et al. Tracheostomy trends in paediatric intensive care. Archives Diseases of Childhood 2021;106:712-14.

2. Powell J, Keltie K, Sims A, et al. A national cohort study of healthcare resource utilization following pediatric tracheostomy (in press) JAMA Paediatrics 2022

3. Roberts J, Powell J, Begbie J, et al. Pediatric tracheostomy: A large single-center experience. Laryngoscope 2020;130(5):E375-E80. doi: 10.1002/lary.28160 [published Online First: 2019/06/30]

4. Perez-Ruiz E, Caro P, Perez-Frias J, et al. Paediatric patients with a tracheostomy: a multicentre epidemiological study. Eur Respir J 2012;40(6):1502-7. doi: 10.1183/09031936.00164611 [published Online First: 20120410]

5. Watters KF. Tracheostomy in Infants and Children. Respir Care 2017;62(6):799-825. doi: 10.4187/respcare.05366 [published Online First: 2017/05/27]

6. Fiske E. Effective strategies to prepare infants and families for home tracheostomy care. Adv Neonatal Care 2004;4(1):42-53. doi: 10.1016/j.adnc.2003.11.011

7. Flynn AP, Carter B, Bray L, et al. Parents' experiences and views of caring for a child with a tracheostomy: a literature review. International journal of pediatric otorhinolaryngology 2013;77(10):1630-4. doi: 10.1016/j.ijporl.2013.07.020 [published Online First: 2013/08/21]

8. Flynn A, Whittaker K, Donne AJ, et al. Holding Their Own and Being Resilient: Narratives of Parents over the First 12 Months of Their Child Having Tracheostomy. Comprehensive child and adolescent nursing 2020;1-11. doi: 10.1080/24694193.2020.1785046 [published Online First: 2020/07/02]

9. Antoniou I, Wray J, Kenny M, et al. Hospital training and preparedness of parents and carers in paediatric tracheostomy care: A mixed methods study. International journal of pediatric otorhinolaryngology 2022;154:111058. doi: 10.1016/j.ijporl.2022.111058 [published Online First: 20220129]

10. Hopkins C, Whetstone S, Foster T, et al. The impact of paediatric tracheostomy on both patient and parent. International journal of pediatric otorhinolaryngology 2009;73(1):15-20. doi: 10.1016/j.ijporl.2008.09.010 [published Online First: 2008/11/21]

11. McCormick ME, Ward E, Roberson DW, et al. Life after Tracheostomy: Patient and Family Perspectives on Teaching, Transitions, and Multidisciplinary Teams. Otolaryngology--head and neck surgery 2015;153(6):914-20. doi: 10.1177/0194599815599525 [published Online First: 2015/08/20]

12. Nageswaran S, Golden SL, Gower WA, et al. Caregiver Perceptions about their Decision to Pursue Tracheostomy for Children with Medical Complexity. The Journal of pediatrics 2018;203:354-60.e1. doi: 10.1016/j.jpeds.2018.07.045 [published Online First: 2018/09/22]

13. Ward E, Morgan T, McGowan S, et al. Preparation, clinical support, and confidence of speech-language therapists managing clients with a tracheostomy in the UK. International journal of language & communication disorders 2012;47(3):322-32. doi: 10.1111/j.1460-6984.2011.00103.x [published Online First: 2012/04/20]

14. Mitchell R, Parker V, Giles M. An interprofessional team approach to tracheostomy care: a mixed-method investigation into the mechanisms explaining tracheostomy team effectiveness. International journal of nursing studies 2013;50(4):536-42. doi: 10.1016/j.ijnurstu.2012.11.008 [published Online First: 2012/12/12]

15. Page BF, Hinton L, Harrop E, et al. The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'. Health expectations 2020; doi: 10.1111/hex.13092 [published Online First: 2020/06/17]

16. Westwood EL, Hutchins JV, Thevasagayam R. Quality of life in paediatric tracheostomy patients and their caregivers - A cross-sectional study. International journal of pediatric otorhinolaryngology 2019;127:109606. doi: 10.1016/j.ijporl.2019.109606 [published Online First: 2019/09/09]

17. Carnevale FA, Alexander E, Davis M, et al. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. Pediatrics 2006;117(1):e48-60. doi: 10.1542/peds.2005-0789 [published Online First: 2006/01/07]

18. Gower WA, Golden SL, King NMP, et al. Decision Making about Tracheostomy for Children with Medical Complexity: Caregiver and Healthcare Provider Perspectives. Academic pediatrics 2020 doi: 10.1016/j.acap.2020.06.004 [published Online First: 2020/06/17]

19. Hebert LM, Watson AC, Madrigal V, et al. Discussing Benefits and Risks of Tracheostomy: What Physicians Actually Say. Pediatric critical care medicine 2017;18(12):e592-e97. doi: 10.1097/pcc.0000000000001341 [published Online First: 2017/09/25]

20. Amar-Dolan LG, Horn MH, O'Connell B, et al. "This Is How Hard It Is". Family Experience of Hospital-to-Home Transition with a Tracheostomy. Annals of the American Thoracic Society 2020;17(7):860-68. doi: 10.1513/AnnalsATS.201910-780OC [published Online First: 2020/04/09]

21. Brenner M, Larkin PJ, Hilliard C, et al. Parents' perspectives of the transition to home when a child has complex technological health care needs. International journal of integrated care 2015;15:e035. doi: 10.5334/ijic.1852 [published Online First: 2015/11/04]

22. Callans KM, Bleiler C, Flanagan J, et al. The Transitional Experience of Family Caring for Their Child With a Tracheostomy. Journal of pediatric nursing 2016;31(4):397-403. doi: 10.1016/j.pedn.2016.02.002 [published Online First: 2016/04/05]

23. Toly VB, Blanchette JE, Alhamed A, et al. Mothers' Voices Related to Caregiving: The Transition of a Technology-Dependent Infant from the NICU to Home. Neonatal network : NN 2019;38(2):69-79. doi: 10.1891/0730-0832.38.2.69 [published Online First: 2019/08/31]

24. Patel MR, Zdanski CJ, Abode KA, et al. Experience of the school-aged child with tracheostomy. International journal of pediatric otorhinolaryngology 2009;73(7):975-80. doi: 10.1016/j.ijporl.2009.03.018 [published Online First: 2009/05/01]

25. Nakarada-Kordic I, Patterson N, Wrapson J, et al. A Systematic Review of Patient and Caregiver Experiences with a Tracheostomy. The patient 2018;11(2):175-91. doi: 10.1007/s40271-017-0277-1 [published Online First: 2017/09/16]

26. Corris V, Dormer E, Brown A, et al. Health inequalities are worsening in the North East of England. Br Med Bull 2020;134(1):63-72. doi: 10.1093/bmb/ldaa008

27. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health 2019;11(4):589-97. doi: 10.1080/2159676x.2019.1628806

28. Altman L, Zurynski Y, Breen C, et al. A qualitative study of health care providers' perceptions and experiences of working together to care for children with medical complexity (CMC). BMC Health Serv Res 2018;18(1):70. doi: 10.1186/s12913-018-2857-8 [published Online First: 2018/02/02]

29. Gerain P, Zech E. Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving. Front Psychol 2019;10:1748. doi: 10.3389/fpsyg.2019.01748 [published Online First: 2019/08/21]

30. Hall N, Rousseau N, Hamilton DW, et al. Impact of COVID-19 on carers of children with tracheostomies. Archives of disease in childhood 2022;107(3):e23. doi: 10.1136/archdischild-2021-322979 [published Online First: 20211209]

31. Lazarus RS. Stress and emotion: A new synthesis. New York: Springer. 1999.

32. Gong S, Wang X, Wang Y, et al. A Descriptive Qualitative Study of Home Care Experiences in Parents of Children with Tracheostomies. Journal of Pediatric Nursing 2019;45:7-12. doi: 10.1016/j.pedn.2018.12.005 [published Online First: 2018/12/31]

33. Lemos HJM, Mendes-Castillo AMC. Social support of families with tracheostomized children. Revista brasileira de enfermagem 2019;72(suppl 3):282-89. doi: 10.1590/0034-7167-2018-0708 [published Online First: 2019/12/19]

34. Spratling R, Lee J. Caregivers experiences in symptom management for their children who require medical technology at home. Journal for Specialists in Pediatric Nursing : JSPN 2020;25(1):e12275. doi: 10.1111/jspn.12275 [published Online First: 2019/10/19]

35. Agarwal A, Marks N, Wessel V, et al. Improving knowledge, technical skills, and confidence among pediatric health care providers in the management of chronic tracheostomy using a simulation model. Pediatric Pulmonology 2016;51(7):696-704. doi: 10.1002/ppul.23355 [published Online First: 2015/12/19]

36. Davis KA, Edgar-Zarate CL, Bonilla-Velez J, et al. Using Didactics and Simulation to Enhance Comfort, Knowledge, and Skills of Nonsurgical Trainees Caring for Patients With Tracheostomy and Laryngectomy. Simulation in Healthcare 2019;14(6):384-90. doi: 10.1097/sih.0000000000000392 [published Online First: 2019/12/06]

37. Baumbusch J, Mayer S, Sloan-Yip I. Alone in a Crowd? Parents of Children with Rare Diseases' Experiences of Navigating the Healthcare System. J Genet Couns 2018 doi: 10.1007/s10897-018-0294-9 [published Online First: 2018/08/22]

38. Golden SL, Nageswaran S. Caregiver voices: coordinating care for children with complex chronic conditions. Clinical pediatrics 2012;51(8):723-9. doi: 10.1177/0009922812445920 [published Online First: 2012/05/09]

39. Cady RG, Belew JL. Parent Perspective on Care Coordination Services for Their Child with Medical Complexity. Children 2017;4(6) doi: 10.3390/children4060045 [published Online First: 2017/06/08]

40. Miller AR, Condin CJ, McKellin WH, et al. Continuity of care for children with complex chronic health conditions: parents' perspectives. BMC Health Serv Res 2009;9:242. doi: 10.1186/1472-6963-9-242 [published Online First: 2009/12/23]

41. Luke A, Luck KE, Doucet S. Experiences of Caregivers as Clients of a Patient Navigation Program for Children and Youth with Complex Care Needs: A Qualitative Descriptive Study. International Journal of Integrated Care 2020;20(4):10. doi: 10.5334/ijic.5451 [published Online First: 2020/12/01]

42. Hartnick C, Diercks G, De Guzman V, et al. A quality study of family-centered care coordination to improve care for children undergoing tracheostomy and the quality of life for their caregivers. International Journal of Pediatric Otorhinolaryngology 2017;99:107-10. doi: 10.1016/j.ijporl.2017.05.025 [published Online First: 2017/07/10]

43. Kirk S. Negotiating lay and professional roles in the care of children with complex health care needs. Journal of Advanced Nursing 2001;34(5):593-602.

44. Harden J. Parenting a young person with mental health problems: temporal disruption and reconstruction. Sociology of Health and Illness 2005;27(3):351-71.

45. Tolomeo CT, Major NE, Szondy MV, et al. Standardizing Care and Parental Training to Improve Training Duration, Referral Frequency, and Length of Stay: Our Quality Improvement Project Experience. Journal of Pediatric Nursing 2017;32:72-79. doi: 10.1016/j.pedn.2016.10.004 [published Online First: 2017/03/28]

46. Brenner MJ, Pandian V, Milliren CE, et al. Global Tracheostomy Collaborative: data-driven improvements in patient safety through multidisciplinary teamwork, standardisation, education, and patient partnership. British Journal of Anaesthesia 2020;125(1):e104-e18. doi: 10.1016/j.bja.2020.04.054 [published Online First: 2020/05/28]

47. Swords C, Bergman L, Wilson-Jeffers R, et al. Multidisciplinary Tracheostomy Quality Improvement in the COVID-19 Pandemic: Building a Global Learning Community. The Annals of Otology, Rhinology, and Laryngology 2021;130(3):262-72. doi: 10.1177/0003489420941542 [published Online First: 20200717]

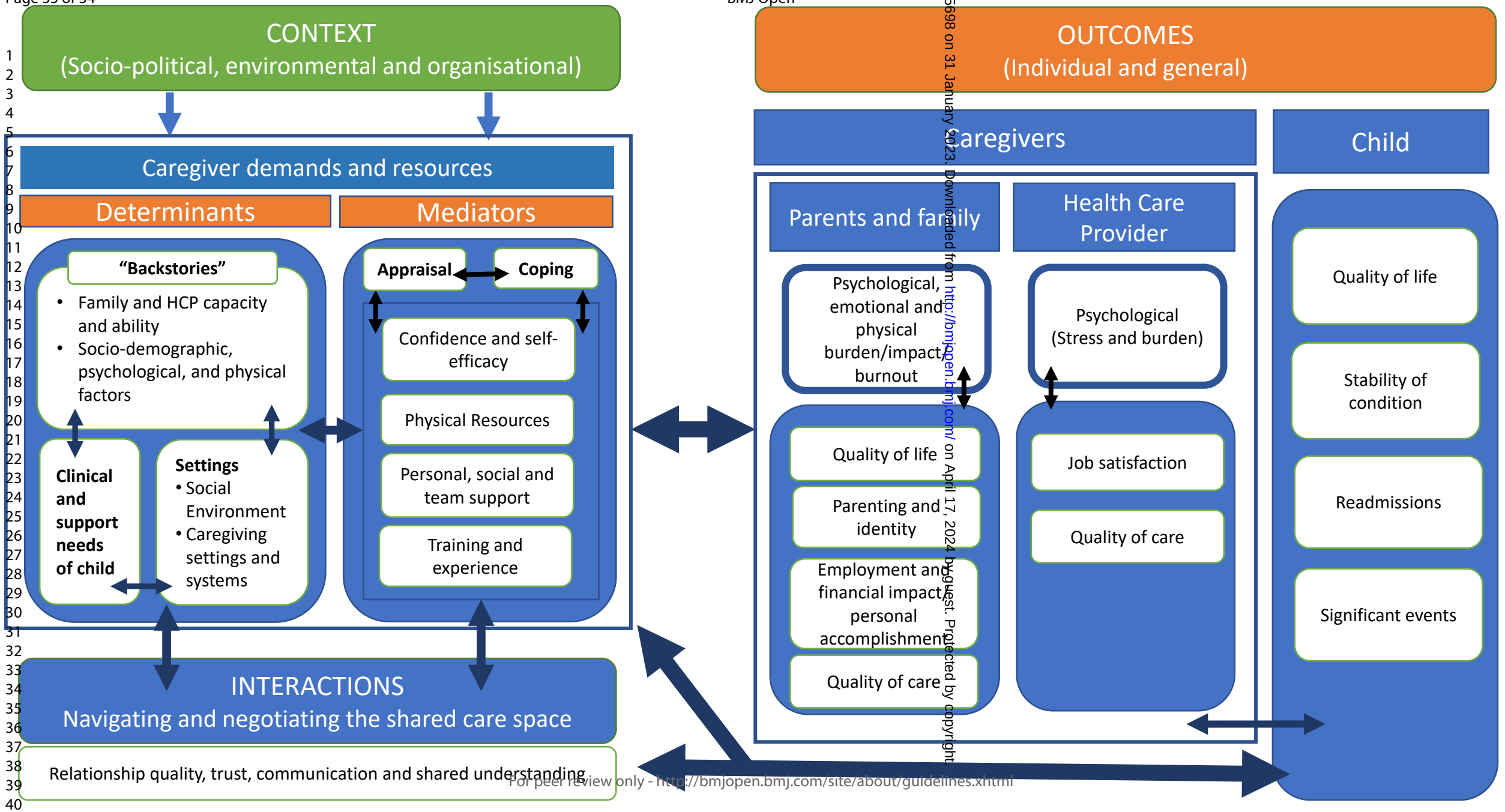
48. McGrath BA, Wallace S, Lynch J, et al. Improving tracheostomy care in the United Kingdom: results of a guided quality improvement programme in 20 diverse hospitals. British Journal of Anaesthesia 2020;125(1):e119-e29. doi: 10.1016/j.bja.2020.04.064 [published Online First: 2020/06/05]

49. McGrath BA, Ashby N, Birchall M, et al. Multidisciplinary guidance for safe tracheostomy care during the COVID-19 pandemic: the NHS National Patient Safety Improvement Programme (NatPatSIP). Anaesthesia 2020;75(12):1659-70. doi: 10.1111/anae.15120 [published Online First: 2020/05/13]

50. Keilty K, Nicholas D, Selkirk E. Experiences with unregulated respite care among family caregivers of children dependent on respiratory technologies. Journal of Child Health care 2018;22(1):46-56. doi: 10.1177/1367493517746770 [published Online First: 2017/12/28]

51. Rafferty KA, Beck G, McGuire M. When Facing Hopeful and Hopeless Experiences: Using Snyder's Hope Theory to Understand Parents' Caregiving Experiences for Their Medically Complex Child. Journal of Pediatric Health Care 2020;34(6):542-49. doi: 10.1016/j.pedhc.2020.06.003 [published Online First: 2020/08/11]

52. Read J. Disability, the Family and Society: Listening to Mothers. Buckingham: Open University Press. 2000.



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.