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Holding their own and being resilient: narratives of parents over the first 12 months of their child having tracheostomy.

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Abstract

Caring for a child with a tracheostomy can be challenging for parents and learning to safely manage their child's airway can be frightening due to their child's breathing issues, complex diagnosis and the difficult decisions they have to make. The aim of this longitudinal narrative study was to tell the stories of parents whose child had a new tracheostomy. Twenty-three narrative interviews were conducted with twelve parents from nine families at three time points over a 12-month period. Data were analysed using a socio-narratological approach. The stories told how parents were able to 'hold their own' despite experiencing shock, emotional upheaval and uncertainty during the period of their child's surgery. 'Holding their own' was possible for parents because resilience played an important part of their journey. Parents continued to be resilient as they adapted to being at home and dealt with ongoing challenging and stressful circumstances. All of the parents told stories reflecting on and recognising that there were times when they exhibited higher levels of resilience and times when their resilience was lower. Looking back on their experiences, parents appreciated that they reframed their initial often negative views about their child's need for a tracheostomy into more positive understandings and a future orientated perspective.

Key words: parents; tracheostomy; narrative; child; resilience; reframe.

Introduction

Tracheostomy is undertaken to create a safe airway for children who have either an airway obstruction or a neurological impairment that can cause breathing problems. The number of tracheostomies performed on children is increasing (Watters, 2017) and, as more care is provided at home, the delivery of care for children with complex health care needs shifts from professionals to parents (Carter et al., 2016). Caring for a child with a tracheostomy presents parents with new and unexpected demands that include skills acquisition and demonstration of competency in caring tasks that parents would not ordinarily require. Typically, parents must acquire skills in tracheostomy care and demonstrate competency before their child is discharged home. This initial period can be challenging for parents (Montagnino & Mauricio, 2004). The few studies addressing parents' experiences of having a child with a tracheostomy, typically report that the psychological burden of providing tracheostomy-related care can be a daily struggle (Harnick et al., 2003; Montagnino & Mauricio, 2004), which adversely affects parents' health (Hopkins et al., 2008). However, some parents have reported the experience of caring for a child with a tracheostomy as having minimal impact on their lives (Hopkins et al., 2008). The need for support and the crises some parents' experience due to the lack of support are common discussion points within the literature (Montagnino & Mauricio, 2004; McNamara et al., 2009). Heaton et al. (2005) found that time demands on the caring role for parents whose child was technology dependent had a negative impact upon them. Although clinical pathways and guidance in relation to tracheostomy management exist in the United Kingdom (NHS Quality Improvement Scotland, 2008; Great Ormond Street Hospital, 2015) and elsewhere, (Lavin et al., 2014) most focus on achieving parent and professional competence in clinical care. None of these pathways or guidance documents encompass the wider needs of the child and family, reflects the absence of their development alongside a model of children's nursing such as family centred care (Kuo et al., 2012).

No in-depth qualitative investigations of parents' experiences of having a child with a tracheostomy have been reported, and longitudinal studies focusing on parents' views and experiences of caring for a child with a tracheostomy are absent from the literature (Flynn et al., 2013). Therefore, there exists limited knowledge about how best to support parents as they transition to caring for their child with a tracheostomy. This paper provides an overview of the stories parents told of their experiences of the first year of caring for their child with a new tracheostomy.

Methodology and Methods

This longitudinal qualitative study drew on narrative inquiry (Moen, 2006) that aimed to explore parents' experiences over the first 12 months of their child having a tracheostomy. A narrative approach was chosen for this study as stories have the ability to resonate in a way that other forms of information often cannot (Polkinghorne, 1998; Riessman, 2002).

Ethics approval

Ethics approval was gained from the University ethics committee and National Research Ethics Service (13/NW/0349)

Methods

Narrative interviews were undertaken by the primary researcher with parents at three time points in the first year of their child having a new tracheostomy. The aim was to interview parents before their child's discharge from hospital, then at 3 and 12 months after discharge. Interviews were timed and arranged at parents' convenience either at hospital or their home or a mutually acceptable location.

The interviews used a semi-structured approach which allowed parents' narratives about their child needing and having a tracheostomy, to unfold. Opening questions at each time point were designed to be very broad (see Table 1); open-ended prompts such as "Tell me more about this?" were used, if necessary, to encourage more detailed story telling.

All interviews were audio-recorded with the parent's consent. Field notes were documented.

Table 1: Key questions asked at interviews

Interview Time Point 1	[Name of child] had a tracheostomy, please tell me about this experience
Interview Time Point 2	How are you getting on?
Interview Time Point 3	Looking back now how are you feeling? Looking forward now, how do you see the future?

Reflexivity was key throughout the study, not least because the primary researcher's other role, as a clinical nurse practitioner providing clinical care for the families in this study, created potential power issues between the researcher and the parents.

Sample and participants

Convenience sampling was used to identify parents whose child had a new tracheostomy from within the catchment area of a children's hospital in the North of England. Recruitment was undertaken over 14 months. An Ear Nose and Throat Consultant initially approached potential participants within 1 to 3 weeks of their child having a tracheostomy. If potential participants demonstrated they were interested, the researcher would provide more in-depth verbal explanations about the study. Potential participants were given up to 48 hours after the researcher had talked to them, to think about the study before being approached about an initial decision.

Data analysis

Transcripts from the interviews were analysed using dialogical narrative analysis, a socio narratological approach (Frank, 2010). Rather than looking for themes the researcher uses narratively driven questions to gain a stronger insight into the main experiences and what the stories had the 'capacity to do'. The socio narratological approach encourages the researcher to seek a movement of thought through their data. Examples of questions that were applied to the data to generate this movement of thought and critical analysis of the data included: What makes this story narratable? and 'What are the forces of fear and desire in the story? Analysis was undertaken by the primary researcher with the support and input from the other authors.

Findings

Twelve parents from nine families took part in the study: three fathers and nine mothers (Table 2). Parent and family details have been altered so they are not identifiable; pseudonyms have been used.

Table 2: Outline demographic data of the families

Families	Participants	Child's age at time of tracheostomy	Medical issues
Greene family: Tom, his mother and father and one sibling	Mother Father	6 weeks	Unexpected breathing issues immediately after birth due to genetic syndrome diagnosed postnatally.
Smith family: Rose, her mother and father and one sibling	Mother	4 months	Unexpected breathing issues postnatally due to complex anomalies.
Jones family: Sam, his mother and father	Mother Father	2 years	An escalation of long standing complex neurological disability.
Carr family: Melody, her mother and father	Mother	3 months	Unexpected breathing issues immediately after birth due to complex anomalies diagnosed postnatally.
Maguire family: Matthew, his mother and two siblings	Mother	4 weeks	Unexpected breathing issues immediately after birth due to congenital abnormality diagnosed postnatally.
Doyle family: Freya, her mother and father and one sibling	Mother	3 months	Unexpected breathing issues due to an airway obstruction postnatally that initially went undiagnosed.
Crabtree family: Louise, her mother and father and one sibling	Mother	11 years	An escalation of long standing complex neurological disability.
Johnson family: Jack, his mother and father and one sibling	Mother	9 months	Unexpected breathing issues due to an airway obstruction postnatally that initially went undiagnosed.
Craig family: Anna, her mother and father	Mother Father	4 weeks	Unexpected breathing issues after birth due to airway obstruction postnatally.

'Holding their own' stories were the key stories told by parents, reflecting both their early experiences prior to their child's tracheostomy as well as their post-surgery experiences Typically, these stories reveal a shift from a time when parents' experiences were typified by a sense of having no control over what was happening to them, to a time when they began to re-establish a degree of control. 'Holding their own' stories can be broadly categorised as two types of core stories: 'Shock, upset and impact' and 'Coming out the other side'; each of these has sub types of stories (see Figure 1). Resilience is a conceptual thread that ran through the stories and is explored in relation to how parents were able to 'hold their own'.

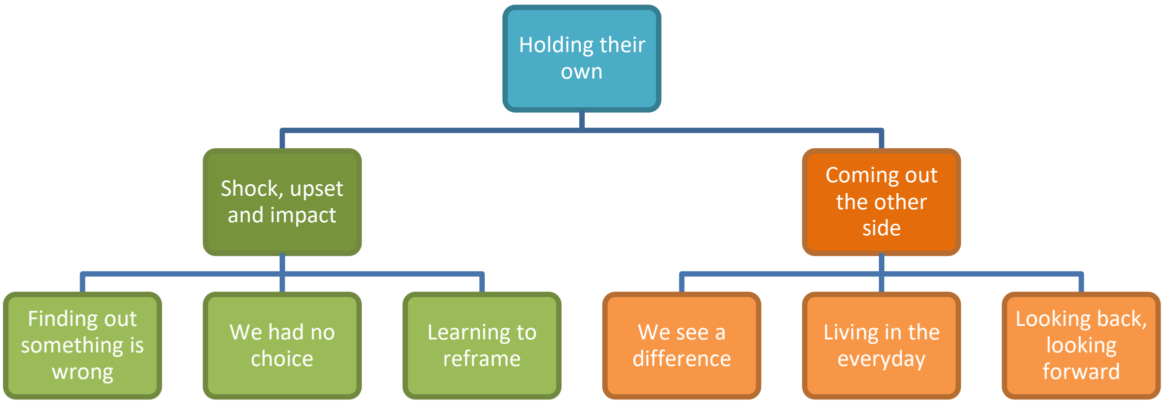

Figure 1: Types of stories that are encompassed within 'Holding their own'

Holding their own

Parents had to 'hold their own' through difficult and upsetting times and although their resilience relating to their child's tracheostomy was initially tenuous, over time, their mind-set about their child's tracheostomy became more resilient as they learnt to accept and deal with their child's tracheostomy both psychologically and practically.

Core story 1: Shock, upset and impact.

The shock, upset and impact story focuses on times of stress, threat and reframing and it is composed of three sub stories. In many of the early stories the parents' focus is on the time when they were 'Finding out something was wrong'; these stories were full of anxiety and reflected the threat facing their child. The 'We had no choice' stories reflect their child's need to have a tracheostomy and the 'Learning to reframe' stories resonate with parents developing confidence and competence in caring for their child.

Finding out something is wrong: Some parents recalled being plunged into a state of shock when they were confronted with their child's immediate breathing problems at birth. Tom's parents spoke of the unexpected medical activity at his birth and their fear for his life:

> *"It was the worst thing; the moment he was born they had a respiratory table, surrounded by about 6 or 7 doctors. We didn't hear him cry at all, I just knew there was a problem. It wasn't for about 20 minutes until someone [doctors] came over and said, 'He's got breathing difficulties, we're doing everything we can" (Tom's father).*

Tom's mother expressed her fear for her "*brand new baby and really not knowing what's going on*". Anna's mother recalled how her daughter had breathing problems at birth which became critical and the midwife activated the alarm alerting the doctors who came in and *"whizzed her off"*.

Other parents who had taken their child home before anyone realised there was an issue initially had to manage their child's *"breathing issues"* without any support or professional guidance and were unaware of the seriousness of their child's condition. Jack's mother recalled how he continued to *"struggle to breathe"* and eventually a scan confirmed that *"75% of his airway was blocked".* Freya's mother recalled her annoyance when she was told her daughter would *"grow out of her noisy breathing".* Sam's parents managed his breathing issues at home for over 12 months before he was diagnosed; his mother explained *"We thought it was normal, the way he breathed, not knowing that he was struggling. It's mad".*

Admission to the intensive care unit was a shocking experience for parents; a clear message was that there "*must be something really bad [wrong] with him" (Tom's father).* Melody's and Anna's mothers recalled this time as being "*very scary and intense" (Anna's mother)* and although acknowledging that admission was *"for the best*" it was a place *"… you never want to be" (Melody's mother).*

One of the toughest and most emotional times for the parents was when they received the news about their child's medical diagnosis and treatment. Tom's father described being in shock, recalling "*wow, hang on from a couple of days of nothing and then you are told he has this and like half a dozen operations".*

We had no choice: Even though parents knew their child might not "*survive*" without a tracheostomy, initial perceptions of tracheostomy were negative and the stories they told were full of emotion. Sam's father described how initially "*we were very objectionable to a trachy"* and Freya's mother said it was her *"worst case scenario".* Parents' objections focused on "*the look"* and how *"people might judge you"* and talked of how a tracheostomy was *"harsh" and "unfair"* on their child. Parents' stories recalling consent and surgery were emotional reflecting their feelings of shock and distress. Anna's mother talked of having *a "little bit of a cry"* because "*the death word"* had been mentioned. Following surgery some parents were *"shock[ed]"* and emotionally *"devastated*" when they saw their child. Louise's mother emphasised how she was emotionally *"devastated".* She remembered her struggle in accepting the tracheostomy and seeing her daughter after surgery and said "*I could not look at her without, crying, even though I knew it was the right thing to do".* However, other parents felt relief in seeing their child's breathing problems stabilised and wished it *"had been done sooner*". Despite initial resistance parents developed resilience about their child's tracheostomy and eventually talked of their initial reactions as being "*selfish"* as, with time, they were able to see the bigger picture. Tom's father explained "*if this simple task for us is to stop him going through that, surely that's a better thing*".

Learning to reframe: Parents' lives took a different turn when their child had a tracheostomy. Parents learnt from their experiences to hold their own and develop resilience in many situations by facing the situation head on. The initial stages of learning to care for their child's tracheostomy were fairly pressurised, intense and testing. Sam's mum recalled how she kept "*trying to put my first tube change off"* but then she became more confident as she knew she "*had to do it".* Sam's father thought his first change was a "*big deal"* and was "*quite emotional"* after the tube had been changed as it was "*something new*". Parents were concerned both about doing the tube change because they knew their child's *"life depends on it"* as well as feeling guilty as they "*wondered what they [child] are thinking.*

Parents looked forward to being discharged and going home but one of their main concerns was sustaining their child's tracheostomy care at home. Reframing their lives at home now their child had a tracheostomy was *"nerve racking"* and parents expressed feeling "*apprehensive"* about leaving the security of the hospital behind. Finding her *"confidence"* was low because of spending so much time in hospital; Louise's mother acknowledged "*worrying*" about her ability to "look *after an artificial airway*" at home. However once at home she reframed this view and realised how she was *"fine, you just get on with it and do it"*.

Parents discussed the challenges they faced when dealing with other people's reactions to their child's situation. Jack's mother remembers how she had to reframe her own view about people's reaction to the birth of her son.

> *"Everyone at my daughter's school knew I had a baby, they were waiting to see him and they been asking is he alright. Now they can't ask again they feel like it's too much, so it goes silent, you feel terrible. But that's how sometimes it is [……silence…………] you just have to go with it and manage it" (Jack's Mother).*

Rose's mother recalled that when she first brought her daughter home she would be upset when people would stare "*when you started giving suction*" and would say *"oh we're so sorry".* However, overtime her reaction changed as she was glad her daughter had a tracheostomy and was alive "*what's there to be sorry about? She here she's alive*"

Core story 2: Coming out the other side

The 'Coming out the other side' story focuses on times that were less stressful for parents and it is composed of three sub-stories (see Figure 1). In the 'We see a difference' stories, the focus is on the time when parents saw a positive change in their child's breathing which brought them relief and hope. The 'Living in the everyday' stories explore times when finding a balance in their lives was important to parents and the 'Looking back, looking forward' stories reflect on their past and future hopes.

We see a difference: One of the most comforting periods of time for parents was when their child's breathing became stable after the tracheostomy had been inserted. Jack's mother appreciated what had been done to keep her son alive:

> *"I am just happy that he is ok. What they have done, we are so grateful. I don't know what would have happened just so glad he survived. The tracheostomy has helped him live and develop him that's what the trachy has done" (Jack's mother).*

Tom's mother remembered how she had *"cried with relief"* following his operation and how Tom looked *"so much happier".* Tom's father recalled how for the first time since his son's birth he could relax and enjoy him as he had "*nothing to worry about".*

Parents talked about how having a tracheostomy had been the right decision for their child because it had been "*the best thing"* and helped their child to "*survive".* Melody's mother explained that the tracheostomy had helped her daughter to *"thrive"* as well as survive. Parents also told stories of how this then led them to reconsider their own initial feelings about a tracheostomy. Sam's mother had expected she would *"be terrible about this trachy'* but recalled that this was not the case and his father pondered whether this was *"because he is our baby [but] you don't even notice it".* Rose's mother talked about how she had overcome her initial reservations about the tracheostomy saying, "*I just get on with it now, she's here, she's alive, she's kicking".* Tom's parents recalled how what seemed "*so huge at the start"* now seemed like a *"dummy [pacifier] but in a different place and we are grateful for it".*

Living in the everyday: Over time parents discovered the importance of working together as a team and that routines were *"important"* within their everyday lives. Managing the tracheostomy became more routine for the parents, and Sam's father said that the tracheostomy was "*old hat now …. it's nothing*". The regular daily routine became more manageable:

> *"It is second nature now, we do it without noticing. Tube changes we do them every Saturday and Melody doesn't notice, we make a big fuss we play with her. Since we've been home it's not really been too bad. She always copes well she can be a bit grumpy afterwards, but she always has done" (Melody's mother).*

Parents became more resilient about and relaxed when caring for their child's tracheostomy, it became a *"basic habit".* As their child got used to the tracheostomy care and became relaxed and "*settled*", parents were *"not as scared".* Jack's mother talked about how her experience of changing his tracheostomy tube has significantly changed over time and how she is now "*happy"* and *"confident"*.

Settling down and becoming more confident with the everyday tracheostomy care meant parents could also provide their child with a normal childhood routine. Parents spoke about getting "*out and about at a baby group*" and how they were *"trying to do the everyday stuff".* Tracheostomy support via social media networks was an important source of help and support to the parents as other parents could provide "*really useful little hints and tips"* and the parents advised *"anybody who gets a baby with a trachy, just to go on them".* Melody's mother talked of the social media site as a "*normal group of friends"* who "*know what you're going through".* Tom's mother explained how she has now "*helped people as well".*

Looking back, looking forward: The most reflective stories and those that showed resilience came when parents took time to think about the past and to consider their hopes for the future. Sam's father offered advice to other parents in the same situation:

> *"…just to go with it, go with the trachy, it won't be a bad decision, an emotive one but not a bad one"*

Looking back, Melody's mother described how she "*fully trusted"* the consultant and how he "*saved"* her daughter's life. Freya's mother talked about how her daughter was now *"doing really well"* and that she *"truly believes"* that this was "*down to the tracheostomy".* However, for Louise's mother, the tracheostomy had been a "*double edged sword, for her [Louise] it's been the best thing, for me not so much but I don't regret it"*; one of the reasons for this ambivalence was that Louise's care package created a constant battle to maintain effective external support. Tom's parents noted the *"difference a year makes"* and said that it would *"not be a disappointment"* for them if Tom's tracheostomy did not come out in the immediate future.

Parents shared their hopes of a brighter future for their child. Jack's mother spoke about the "*big surgery"* to repair his airway and how she expects that *"everything should go well, I am very* *hopeful".* Sam's father talked of his hope that his son's tracheostomy might be removed and described this as "*the Shangri-La"*. Other parents were just grateful that their child was still "*here and ok* "and they were *"taking it from day to day".*

Discussion

'Holding their own' was evident in the stories parents told of their child's diagnosis and subsequent tracheostomy surgery but even when they were in the middle of the shock, emotional upheaval and uncertainty about their child's life threatening breathing issues they demonstrated some resilience. Although parents in other studies have reported 'uncertainty' about the medical state of their child with a tracheostomy (McNamara et al., 2009) and described the period of diagnosis and surgery as being most stressful and intense period of time for them (Callans et al., 2016), no other studies have explored this through a longitudinal approach. This study shows how parents get on with their lives despite the challenging circumstances they face.

One of the most significant challenges faced by parents was the major, life-altering decision for their child to have a tracheostomy, though many felt that they had no choice. Carnevale et al. (2006) also found that making a choice about life-support decisions for their child is not a true choice for parents, when the alternative is to let their child die.

This study identified several key points in the trajectory of a child having a tracheostomy, which were particularly emotional and challenging to parents. These key points showed parallels to those noted by literature reporting other challenging scenarios once admitted to intensive care unit (Colville et al., 2008; Baia et al., 2016) and parents' mastery of core tracheostomy care skills for their child to be discharged home (Callans et al., 2016). Being at home was also a key point for parents and was not always easy, so tested parents' resilience. Parents continued to face challenges not only from their child's changing needs but also because of the need to battle for care packages; as others addressing the complex care of children at home have reported (Watson et al., 2002; Townsley et al., 2004). One specific challenge for parents of children with a tracheostomy is the disruption that can occur due to the lack of knowledge from care providers about tracheostomies (Callans et al., 2016).

'Holding their own' whilst protecting their child from unwanted attention and sympathy from other people was important to the parents in this study; they wanted their child to be treated as normal and live a normal life as possible. As with other studies, this 'trying to live a normal life' was a positive way of parents incorporating their child's complex needs into day to day family life (Rehm et al., 2005). The parents made it their mission to make their child's life meaningful and to give them as many opportunities as any other child. Due to a resilient mind-set parents were able to reframe their beliefs and lives and try and create a sense of normality and positivity, even if this was sometimes difficult. Such an approach to life is valuable for families, given that when parents have positive expectations for the future they experience less anxiety (LaMontagne et al., 2003) and more life satisfaction (Bailey et al., 2007). Novick et al. (2009) discuss the concept of "emotional muscle" (happiness and sturdiness in the face of life's ordinary and extraordinary challenges) and link it to resilience.

Parents valued and discussed how important it was to draw upon the experiences, reassurance and empathy of other parents whose child had a tracheostomy via social media. Their engagement with online support is not surprising as other studies show that individuals increasingly rely on social media to communicate and share information (Wynter et al., 2015; Swallow, 2017). This study has highlighted the different ways parents 'Hold their own' throughout their child's diagnosis and subsequent tracheostomy surgery drawing on their own and other people's experiences and resilience.

Conclusion

Using a longitudinal narrative approach to this study has provided unique insights over a 12-month period, revealing the ways in which parents were able to 'hold their own', through emotional and distressing times and to develop confidence and competence in caring for their child's tracheostomy. Along the way, their perspectives about their child's tracheostomy shifted from a sense of being overwhelmed to generally feeling more resilient and hopeful for their child's future.

Relevance to practice

The findings from this study aim to enhance the support given to parents by health and social care professionals. In particular, support for parents is needed at key times of high emotion such as when they have to make big decisions when their child's life is in danger. The narratives have the potential to have a wider influence in society as they reveal the need to educate and challenge the attitudes of the public in relation to the appearance and needs of children with a tracheostomy. These stories are presented in the hope that they will "animate" (Frank, 2012) health and social care professionals to reflect on them and take these stories forward to instigate change in their practice with a sense of purpose.

Conflict of interest

The authors declare no conflict of interest.

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