A Narrative Inquiry into the stories parents tell of having a child with a tracheostomy.

By

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Student Declaration.

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or academic or professional institution.

I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work .

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ABSTRACT

Aim of the study:

Caring for a child with a tracheostomy can be challenging and time consuming for parents. The personal challenge to manage their child’s airway safely can be a frightening prospect. However, there is a lack of longitudinal qualitative research on parents’ views and experiences of having a child with a tracheostomy. This longitudinal study aimed to tell the stories of parents whose child had a new tracheostomy.

Methods:

Narrative inquiry was adopted as the methodological approach for this study, which explores parent’s stories at three time points during the first 12 months following their child having a tracheostomy. A convenience sample of parents whose child had a tracheostomy was recruited**.** Twenty three narrative interviews with nine families (3 fathers and 9 mothers) took place. The data have been analysed using socio-narratology (Frank, 2010) which allowed specific questions to seek a movement of thought through the data.

Results:

The findings revealed that the parents initially experienced shock, emotional upheaval and uncertainty about their child’s condition. As their child’s health condition settled (post tracheostomy) life became calmer and parents showed the capacity to function. However, even when their child had returned home the parents continued to experience times of stress. The theoretical underpinning of this study is the process of resilience. The ABC-X model of parental resilience: a process of reframing, underpins the discussion in this study. The model encompasses the interplay of risk factors and protective factors. The parents were able to reflect and recognise that there were times when they exhibited higher levels of resilience and times where their resilience was lower. One of the key aspects of the parents’ building resilience over time was the elasticity of the experience, which reflects the parents’ ability to be stretched by situations and to reframe their lives and beliefs, arriving at fresh understandings as a result of their experiences.

Conclusion:

Acknowledgement that parents experience a protracted process of building resilience after their child’s tracheostomy would enable professionals to provide ongoing support throughout this period of reframing their lives.

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ACKNOWLEDGEMENTS

> *"A dream you dream alone is only a dream. A dream you dream together is reality"*
>
> *John Lennon*

I had a dream to conduct a piece of research about children who needed a tracheostomy. I have now have had that opportunity to live the dream and conducting this research has been an invaluable journey. My dream could not have been achieved without certain people. I share the following acknowledgments:

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Let the stories carry on.

GLOSSARY

BNIM:	Biographic-Narrative Interpretive Method.
CASP:	Critical Appraisal Skills Programme.
CCC:	Child-centred care.
CCN:	Children's Community Nurses.
Clinical commissioning Groups (CCG):	Clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.
Complex needs:	A person has multiple inter-connected needs that span medical and social issues.
Continuing care:	A package of ongoing care that is arranged and funded by the NHS (and in some areas social care), where the patient has been found to have a primary health care need such as disability or complex health care need.
Direct payments:	Local health and social care payments for people who have been assessed as needing help from social services, and who arrange and pay for their own care and support services.
DNA:	Dialogical Narrative Analysis
ECM:	Every child matters
ENT:	Ear Nose and Throat.
FCC:	Family-centred care.
GIRFEC:	Getting it right for every child.
GRAMMS:	Good Reporting of A Mixed Methods Study.
GTC	Global Tracheostomy Collaborative
LTV:	Long term ventilation.
NSPCC:	National Society for the Prevention of Cruelty to Children.
NHS:	National Health Service.
OSOP:	One sheet of paper.

PFCC:	Patient and family-centred care.
RCN:	Royal College of Nursing.
Seldinger technique:	Insert a suction catheter into a smaller tracheostomy tube and guide the catheter into the tracheostomy stoma. Slide the tube over the catheter into the stoma and remove the catheter.
Stridor:	A high pitched breathing sound.
Subglottic stenosis:	Narrowing of the airway below the vocal cords.
Tracheostomy:	A tracheostomy is a surgically created opening in the neck with a hollow tube inserted called a tracheostomy tube.
Tracheotomy:	The American version of the spelling of tracheostomy.

CHAPTER 1: IN THE BEGINNING

I will love the light for it shows me the way,

yet I will endure the darkness

Because it shows me the stars.

Og Mandino (1963).

This chapter is an introduction that outlines my interest in exploring parents' experiences of their child having a tracheostomy and sets the scene for my thesis. As a clinical nurse practitioner who, for over fifteen years, has cared for families and their children who have a tracheostomy, I have had a desire to improve practice and find out more about their experiences. Having witnessed parents' journeys and seen how their lives have changed, I have often reflected on how beneficial it would be to collect their stories. Now, as a result of this study, nine families have had the opportunity to share their experiences and tell their stories. However, before I share these stories, I present the background, literature and the methodology chapters. In this first chapter I will discuss the historical and clinical background to tracheostomies, give an overview of parenting a child with a tracheostomy, with a particular focus on children with complex needs and teaching parents clinical skills. I also present background information on models of care that underpin children's nursing, I consider the context of children's healthcare and provide an overview of the policy context underpinning complex health care for children.

Stories as a starting point

I have been a nurse for over 34 years. I had the privilege of nursing adults for 20 years, and over the last 14 years I have nursed children. My interest in nursing children came when I was undertaking my BA (Hons) degree; I was then an Ear Nurse and Throat (ENT) nursing sister in adult care. When my present role as

ENT nurse practitioner was advertised, the job description suggested some very exciting opportunities to develop a role in nursing children with ENT conditions. One of the main roles was to develop and improve the services for children with tracheostomies and their families. This has included developing pathways of care, services policy and practice, discharge planning, training for both staff and parents in the clinical skills of managing tracheostomies, professional relationships both with children and families and with health professionals in the Trust and community. The catchment area for my role is large and covers the North West of England, North Wales, Shropshire and Isle of Man.

My clinical practice has allowed me to be involved with parents and their children with a tracheostomy and this had provided me with the opportunity to be a part of a range of different experiences and journeys. Prior to starting this study, I had become increasingly aware that parents' journeys and experiences needed to be shared. I believed that these experiences had the potential to create evidence to enhance practice and provide future parents with an opportunity to learn from parents who had already experienced the journey. I had also seen a rise in the number of tracheostomies performed in children over the years and an increase in my clinical caseload. My experiences with these families and the journeys they took over the years encouraged and motivated me to explore my practice by undertaking research. I wanted to improve the health care and services for my patients.

Thinking back on my clinical experience and the many untold stories that motivated me to do this study, I particularly remember having conversations with parents about their experiences when things were chaotic for them. I present two stories from the many that I could have re-told, these are 'The gentle giant' and 'The comeback mother.'

'The Gentle Giant'

Josh's father spoke to me of how terrified he was about changing his son's tracheostomy tapes (tapes secure the tracheostomy tube in place around the neck). His son had been born prematurely with a low birth weight and had needed a tracheostomy after the first few weeks of his life. Josh’s father was a sportsman with large hands, and doing his son’s tapes was a challenge to him that often left him frustrated, but he never gave up, spending many hours on the ‘trachy doll’ (a doll with a tracheostomy in situ that is used as a training aid) practising the tapes, and eventually he became the ‘gentle giant’ of the tape change.

‘The Comeback Mother’

Patrick’s mother had battled with herself over changing her son’s tracheostomy tube - she would try really hard to watch Patrick’s father change the tube, but she would run from the room in tears before it was performed. I particularly remember talking with Patrick’s mother about her concerns for quite a while and she told me how scared she was because she felt she was inflicting pain on her son. More than anything Patrick’s mum was upset with herself because she knew that a tracheostomy had saved her son’s life, but it took her some time to face and accept that a tube change was part of caring for his tracheostomy. There were times when she thought she would never change the tube, but then one day, out of the blue, she suddenly found it within herself to change the tube. To me she became the ‘Comeback mother’.

These stories remind me of the challenges that parents face and the ways in which they have to dig deep to undertake their child’s tracheostomy-related care. I learned a lot from Josh’s father and Patrick’s mother, and the stories they and some of the other parents shared with me as a clinician helped to shape my study. Both Josh and Patrick needed a tracheostomy for a few years of their early lives, although both are now decanulated (tracheostomy removed) and have been discharged from specialist nursing care. The stories of these children and parents go on without me.

Prior to starting this study, I had little experience of research but I had always wanted to learn more about and be involved in research. In 2001, I set about starting my research journey by undertaking my degree, and I took a module in research and developed a research proposal for my dissertation. I then applied for a Master’s degree in 2006, which took my research experience to the next level, giving me my first opportunity to carry out a research study. My dissertation was on the discharge planning experiences of parents whose child had a tracheostomy. I used a mixed method approach to this research and gained some valuable experience into developing a research proposal, the ethics approval process, interviewing, developing questionnaires, data analysis and presenting my findings. This experience was a challenge but also insightful; I was addicted. I still can remember feeling a sense of loss and yet happiness, the day I had my dissertation bound. This spurred me on.

I had become aware from examining previous literature surrounding parents' experiences of having a child with tracheostomy that there was limited research in this field. In particular, there was a lack of robust qualitative work with parents, especially fathers, and there had been no longitudinal studies undertaken. This limited evidence and my desire to build on my research experience by focusing on children with tracheostomies, was a motivating factor to apply for an MPhil/PhD. I believed this would allow me to develop a research study in a field of practice where I wanted to make a positive contribution to improve care, and about which I was very passionate. Pursuing a PhD was therefore the next logical step on my research journey.

Significance of research

Tracheostomy is undertaken to create a safe airway for children who have either an airway obstruction or a neurological impairment. The number of tracheostomies performed is increasing year on year (Wilson, 2005). This in turn has had an impact on acute hospital and community care settings, as more care occurs at home, and the delivery of care shifts from professionals to parents. There are few studies addressing the care experiences of parents whose children need a tracheostomy. This means that there is a paucity of evidence for health or social care professionals to draw on to begin to develop an understanding of the experiences of parents caring for a child with a tracheostomy. This study is significant in that it provides fresh insights into the experiences of parents over a 12 month period, but following parents' journeys in one children's specialist hospital and then at home at three time points. The evidence generated by this study has the potential to improve practice and the quality of care delivered to this client group by health and social care professionals.

Historical context to tracheostomies

In the following section, I present the history of tracheostomy, and the medical reasons why children have tracheostomies in order to provide some background context.

Figure 2.1: Image of tracheostomy tube in position

A tracheostomy provides a channel made through the neck for effective respiration and removal of tracheobronchial secretions (Lindman & Morgan, 2010). A tracheostomy is an opening created at the front of the neck so a tube can be inserted into the windpipe to help a person breathe. The surgical procedure of performing a tracheostomy is an ancient one and dates back as far as 3600 BC to the early Greek and Egyptian civilisations (Sittig & Pringnitz, 2001). Historically there was trepidation about performing a tracheostomy, as is illustrated in the following description:

> *"It was a frigid afternoon that day in Virginia December 1799 as three Physicians gathered around a dying man. The Physicians gave the man sage tea with vinegar to gargle but it nearly caused the patient to choke to death. The patient's condition continued to deteriorate as he struggled for breath. One of the Physicians was aware of tracheostomy procedure but was reluctant to attempt it on such a famous person because the procedure was considered futile and irresponsible. Soon the patient became calm and died. This story describes the death of*

> *George Washington. While arguments still persist about his death the most popular theory is that he died from an upper airway obstruction caused by bacterial epiglottitis”* (Morens, 1999, p1845).

In the early 1800s, the most common reason for children to receive a tracheostomy was diphtheria and this really did not change until the 1930s when tracheostomy was widely used in the treatment of poliomyelitis (Stoller, 1999). These diseases caused the patient to have an airway obstruction secondary to an infection and tracheostomy was performed to aid breathing. Sinice the 1960s, changes in the epidemiology of infectious diseases and the capabilities of medical technology have altered indications for and implications of tracheostomy in children (Lewis, et al., 2003). For example, advancements in the 1970s in neonatal care saw more premature infants surviving initial respiratory challenges, but developing subglottic stenosis (narrowing of the airway) as a result of lengthy periods of intubation, and inappropriate (often too large) intubation tubes which caused necrosis of the tracheal mucosa and the need for ventilation.

Today, tracheostomies are performed to provide a safe airway in children and adults who have either an airway obstruction or a neurological impairment (Caron, Derkay, & Strope, 2000). Children with airway obstruction and neurological conditions are a growing population, necessitating an increasing need for tracheostomies (Spratling, 2012). The length of time that an individual child requires a tracheostomy varies; some children only require it for a short time, while for others it may be a long-term measure. In general, short-term tracheostomies are used for airway obstruction problems, whereas neurological conditions require longer-term support. A specialised group of children require a mechanical aid (ventilator) for breathing to be attached to their tracheostomy (Jardine, O’Toole, & Wallis, 1999). Children requiring Long Term Ventilation (LTV) generally have life-limiting or progressive neurological conditions. However, both the literature and experience from clinical practice shows that a growing number of children require only a tracheostomy, without any form of additional breathing device (Corbett & Clarke, 2007; Serra, 2000). For parents, the need for their child to have a tracheostomy often comes as a complete shock, and learning to accept this and care for their child is a challenge. Potential risks associated with tracheostomies include airway obstruction, mucus plugging, tube displacement, bleeding and infection (Dougherty & Lister 2008; Tamburri, 2000). All of these risks can lead to a respiratory arrest (Day, Iles, & Griffiths, 2009) and require constant care and management to ensure reduction of risks.

Having briefly considered the history and medical reasons for tracheostomy, in the next section I present an overview of parenting a child with a tracheostomy and the uncertainty often associated with parenting a child with complex needs.

Parenting a child with a tracheostomy

The transition into parenthood usually has a predictable pathway and this includes changes in life, relationships and work. Most parents will have planned their immediate future following the birth of their child and organised their child's care (Bornstein, 2001). From my own experience as a parent the expectation of becoming a parent is an exciting yet daunting prospect and comes with a whole range of feelings about your child's future life. The challenges of parenthood can often be rewarding, and these challenges and rewards can be even greater when the child has a complex health care condition (MacDonald & Callery, 2008), which often requires parents to undertake extraordinary care and attention to their child's needs (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). The journey faced by such parents requires personal strength and stamina. Overall, the child's complex health needs can be disruptive to parenting and family life, emotionally distressing, and can impact on what is already a daunting prospect (Valkenier, Haynes, & McElheranmake, 2002). In particular, when a child needs a tracheostomy, parents are often confronted with three challenges; a child who has breathing problems, complex diagnoses, and the need for difficult decisions.

Parents in the UK whose children have a tracheostomy must acquire skills in tracheostomy care and demonstrate competency before their child is discharged from hospital. Training parents to care for their child's tracheostomy requires careful planning and a systematic education programme, which includes learning about suctioning, stoma care, tube changes and resuscitation (Fiske, 2004).

Parents can often be initially overwhelmed with the expectation of having to deliver their child’s tracheostomy care and they can face challenges to their knowledge and confidence (Hettige, Arora, Ifecho, & Narula, 2008). Support for parents in managing these and many other challenges (such as managing other siblings, getting the right amount of sleep) may be required, and these are outside the remit of universal or specialist health services.

Continuing care

Parents of children requiring complex care may require a package of additional health support known as continuing care (Department of Health, 2016). For some families, funded home-based care for their child with a tracheostomy is required, and these packages of care need to be in place before discharge (Fiske, 2004). Some families experience a simple discharge whilst others need a far more complex discharge involving multi-agency planning and a longer stay in hospital (Stephens, 2005). Applying to the local clinical commissioning group (CCG) for this care can often be time consuming and delays discharge home for most families (Ludvigsen & Morrison ,2002; Noyes, 2002). The decision to have a care package for their child can be a difficult one to make and can add extra pressure on parents’ lives. Typically, parents have to go through the following process: multidisciplinary planning meetings, continuing care assessment that goes to panel (CCG), and recruitment, selection and training of a home care team (Department of Health, 2016).

In the next section I will present an overview of the central tenets and goals of children’s nursing.

Children’s nursing: models of care.

Historically, hospitals maintained rigid visiting policies preventing parents from seeing their child for long periods of time (Paliadelis & Cruickshank, 2005). However, it is now recognised that the family is the constant in a child’s life and nurses must work together with the family to develop the best plan of care for a child (Kuok, Hotrod & Arrange, Kuhlthau, Simmons, Neff, 2012). Although there are many different nursing models, those which reflect the importance of the child and their families are the ones that are most frequently used within the delivery of children's healthcare. In this next section, I will present three relevant models of care in children's nursing: family-centred care (FCC); child-centred care (CCC), patient and family-centred care (PFCC). Most emphasis is placed on FCC as this is the most ubiquitous model. The other two models are presented as alternatives to FCC.

Family-centred care is the main model of care that underpins children's nursing.The philosophy of FCC is founded on the collaboration of the family, nurse and allied health professionals to plan, provide and evaluate care. This model aims to ensure that health care is planned around the whole family (Shields, Pratt, & Hunter, 2006). Family-centred care is based on three core principles; partnership, participation and protection (Franck & Callery, 2004). These core principles shape my practice as a nurse practitioner when caring for families whose child has had a tracheostomy. Acknowledging the core principles of FCC has allowed me to be grounded in my approach to care for children by involving them and their families in all aspects of their care. FCC also supports my development of mutually beneficial partnership working with other professionals.

Family-centred care underpins children's nursing in many different settings, regardless of whether children are in an acute phase of illness, receiving complex care in a hospital, or in an ongoing phase of care at home. Family-centred care is a model used across a diversity of children's needs and is considered best practice in providing rehabilitation to children with disabilities and special needs (King et al., 2004). Evidence shows that children with complex needs will do better if they have access to comprehensive, family-centered, culturally competent co-ordinated care (Feeg, 2001).

However, despite its widespread use and a general sense of support for its goals, FCC is not without critique. Family-centred care has historically considered the family as a traditional unit (mother and a father and 2 children) who will be involved in caring for their child; this family unit has altered (Jolley & Shields, 2009). However, the concept of family is not a simple or single-dimensional one; families can include blended families, single-parent households, adoptive homes, same-sex couples, and members of the extended family. Although the model of FCC has evolved over the years to improve and accommodate change, there is plenty of evidence to show that FCC is rarely implemented perfectly (Shields, 2015; Foster, Whitehead, & Maybee, 2010; Harrison, 2010; Shields, Kristensson-Hallstrom, O'Callaghan, 2003). Issues such as inconsistent approaches, lack of knowledge about children's healthcare, unclear definitions, poor communication and lack of negotiation with parents means that studies report that FCC is rarely fully achieved (Espezel & Canam, 2003; Ygge, Lindholmn, & Arnetz, 2006).

The challenges inherent within FCC do not just lie with professionals; parents have reported feeling obliged to carry out their child's care. This can be because of concerns parents have about the implications for their child's care if they challenge the system, including the consequences of challenging nurses' expectations of them (Coyne & Cowley, 2007; Coyne, 2008). Some parents have reported resentment of the increasing expectations placed upon them by professionals (Power & Franck, 2008). Shields, Young and McCann (2008) argue that FCC should not put pressure on parents to carry out their child's care, especially if they do not wish to, or if they feel unable to carry out the required care.

Other tensions exist in relation to delivering family-centred care. Nurses have reported that time constraints resulting from technical procedures, paperwork, administration duties and lack of resources mean they are both unable to deliver FCC and feel powerless to make any changes (Coyne, 2013). Nurses (including myself) often depend on parents as a critical resource, and recognise that workloads, understaffing, increased patient acuity and technical care, increased throughput, more medical tasks and a lack of organizational and managerial support mean that FCC is often not delivered effectively (Coyne, O'Neill, Murphy, Costello, & O'Shea, 2011). Kuo, Houtrow, Arango, Kuhithau, Simmons & Neff (2012) state that there are three main barriers to FCC: understanding of FCC; support in practice; and high-quality research that can guide hospitals, health systems, and policy makers. Bellin (2011) reported that parents and professionals indicated that in order for FCC to improve, continued professional growth in provision of holistic and comprehensive services is needed to meet the multifaceted needs of children with special health care needs and their families .

A model gaining traction within the academic children's nursing community as an alternative to FCC is Child-Centred Care (CCC). The importance of bringing the child to the forefront of their own health care is key to CCC (Carter, Bray, Dickinson, Edwards, & Ford, 2014). Child-centred care aligns to other movements that aim to make services child-centred. Making children's health care practice child-centred is one of the drivers of the *Getting it right for every child* agenda in Scotland (Scottish Executive, 2010). The challenge for nurses and health professionals is to position the child at the centre of all stages of their health care process, thus ensuring that they are informed about their care and provided with choices about their care. The key difference between FCC and CCC is that the latter shifts the focus from the family (whilst still accepting that the family is of fundamental importance) to the child, acknowledging their agency which is often lost within the professional-parent relationship that seems to dominate FCC (Carter et al., 2014; Coyne, Hallstrom, & Soderback, 2016). Child-centred care aims to promote the fundamental principles of protection, promotion and participation and the rights of children and young people (UNCRC, 1989), and to strengthen the view of the child as a person representing their own experiences (Coyne et al., 2016). In contrast to FCC, child-centred care overtly takes into account the social context in which children exist, and clearly views the child as a social actor in their own right (Carter et al., 2014).

Another alternative model of care that has potential for children's nursing takes elements of both FCC and CCC, as it acknowledges that care should be both Patient and Family-Centred Care (P&FCC). This is an established model of care for adults, and one of the key elements of this model recognises and respects the knowledge and expertise of the patient and the family (Institute for Patient & Family Centred Care, 2004, 2015). Patient and family-centred care is based on the recognition that patients and families are essential allies for quality and safety;

the core concepts of this model are dignity and respect, information sharing participation and collaboration (Johnson & Abraham, 2012). However, when faced with caring for a child with complex health care needs, families can confront a number of additional challenges such as stress and the emotional response to their situation. A criticism of models such as FCC is that whilst they are good in focusing on the person/child and their family, they fail to focus attention or consider other theoretical elements that are of relevance to contemporary nursing care, such as stress and adaptation (Kuo et al., 2012).

The admission of a child into hospital is very stressful for all parents but this can be intensified by complex diagnosis, critical care admissions and life-threatening episodes (Foster, Whitehead, Maybee, & Cullens, 2013). Increased demands for the care of a child with a complex health care needs such as having a tracheostomy can have implications for the psychological and physical well-being of parents (Brehat, Kohen, Raina, Walter, Russell, & Swinton, 2004). Children and young people with complex health needs and their families often require high levels of physiological and psychological support and often these needs are not met (Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, 2012).

Consideration of the specific needs of children and their families with complex conditions, which are key to FFC (see pp, 26), should be part of any approach to nursing practice. Leiter (2004) argues that training parents to provide competent care for their children with complex needs is inherent within FCC, as is the need to support parents to undertake more responsibility in their child's care management and to be able to act as advocates for their child.

There seems to be less attention from professionals to other key elements of family-centred care such as recognising the uniqueness of children. By empowering parents to shoulder more responsibility for the care of their child and their family with complex health care needs, potentially there is a loss of focus on other important elements of family-centred care, such as the development of true collaborative relationships between families and health-care professionals (Mackean, Thurston & Scott, 2005).

Traditional efforts to understand and explain families' responses to stressful situations have been centred on the relations between the stressful event and its associated hardships, the outcome of the stress and the intervening factors. There are various models of parental stress and coping that professionals can refer, to although these do not frequently inform children's nursing practice. The Disability-Stress-Coping model (Wallender & Varni, 1998) considers three categories of risk factors (disease/disability parameters, functional dependence and psychosocial stressors), and three categories of resistance factors (intrapersonal, socioecological and stress processing) that directly or indirectly affect the adaptation of parents raising children with disabilities. However, the Double ABC-X model (McCubbin & Patterson, 1982, 1983a, 1983b) does account for the family process, the mediating effects of various family resources, coping patterns, and perceptions and adaption (these models are discussed further in Chapter 6, Resilience theory, P.176). Although much less utilised than FCC, models such as the Disability-Stress-Coping model and the Double ABC-X model have the potential to be valuable guides for professionals to support and strengthen families at a time of crisis (Walsh, 2003; Krstic, Mihic, & Mihic, 2015).

In conclusion, the concept of centering care on the child and their family is evident in models such as FCC, CCC and PFCC and is viewed as a fundamental concept in the provision of high quality nursing care for children and their families. However, evidence shows that implementation of FCC does not occur without issues for both nurses and families. Newer models of care such as CCC and PFCC which advocate a child-centered focus are likely to face similar challenges to FCC, and the same is likely to be true for the implementation of models such as the Double ABC-X model. Getting the care right for children with complex needs is especially challenging for children's nurses to implement, as the needs of the children and families are high and the resources available to nurses are limited.

The context of children’s healthcare: a consideration of national and international policy and guidelines

In this section I will present an overview of the context of children’s health care and consider the broad key policy guidelines of relevance to children within the United Kingdom (UK), with reference to some international directives. The focus of this research study was to seek the views of parents whose children have tracheostomies and this section will consider how ‘complex needs’ are conceptualised and represented in public policy, nationally and internationally.

Children’s health and well-being

According to the World Health Organization (1948, p100) ‘‘health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. Many advances have been made in child health and one of the greatest success stories of the last century has been protecting children through immunisation and the eradication of certain diseases such as diphtheria (McCullers & Dunn, 2008). Major scientific advances in medicine and genetics (Childs & Kansagra, 2007) and new health care facilities have touched the lives of some children in the world today. However, there is still a long way to go to ensure that the health and well-being of all children are optimised and that the rights of all children are ensured. For example, child labour is still acceptable in some countries; this is one of several issues related to child health and abuse that international organisations such as UNICEF (2013a, 2014) campaign about to improve child health and well-being.

Safeguarding the rights of children is truly a global issue applicable to all nations, and key to this is ensuring that policy makers address concerns about the impact of poverty, health inequalities, and maternal health on children (Marmot, Allen, Goldbatt, Boyce, McNeish, & Grady, 2010). Effective policy to tackle the health challenges must address the underlying social conditions and determinants of health that make disadvantaged people including children more vulnerable than those not exposed to disadvantage (Marmot, 2010; Marmot & Allen, 2014). While it might be expected that the UK would be a high achiever in this field, in fact this is not the case. In 2007 the UK was ranked bottom out of 21 industrialised countries for child well-being (UNICEF, 2007), and by 2011 it only had moved up to 16th position out of 29 nations (UNICEF, 2013b). These reports paint a grim picture about child well-being in the UK. The UK has one of the highest mortality rates for children and young people in Western Europe and we continue to have problems in reducing poverty and children's inequalities (Roberts, 2017). The Royal College of Paediatrics and Child Health (RCPCH, 2017) stated that the lack of robust data means that children with the greatest need have the potential to be left unsupported; a more recent report by the RCPCH (2018) suggests that whilst the health of infants, children and young people has improved over recent times, there is still a lot to achieve.

Although overall child health has improved in Europe (Wolfe, Thompson, Gill, Tamburlini, Blair Van Del Bruel, Ehrich, Pettoello-Mantovani, Janson, Karanikolos, & McKee, 2013) health professionals still know there are challenges to improve child health and well-being, both in the UK and internationally (Cheug, 2018). One of the key challenges is effectively implementing the rights of the child and young people.

The rights of the child

The rights of children and young people and the need to improve standards of health care have been developing in public policy since the ratification of the *United Nations Convention on the Rights of the Child* (UNCRC) (1989).The UK is a signatory of the Convention. The UNCRC provides the basis for advocating the health and development of children and young people. The 54 articles of the UNCRC (1989) set out the human rights of children and the standards to which all signatory governments must aspire in realising these rights. Article 23 specifically recognises the rights of disabled children to enjoy a full and decent life, and the right to receive high quality health care.

It has been argued that much more can be done to integrate basic human rights into polices at national and European levels, and that until governing bodies are willing to accept the UNCRC the outlook for child health in Europe will remain uncertain (WHO, 2008, 2012). Fundamental to the Convention is the acceptance of an image of childhood that considers children as autonomous human beings. The image of the autonomous child is argued by Freeman (2007) as part of the evolution towards a more human way of dealing with children in both practice and policy. However, one concern raised in relation to the concept of the autonomous child is that this leaves the child with the responsibility to realise their own rights and to know her or his own needs and interests and to be able to deal with them adequately, just like an adult (Benporath, 2003). Article 12 of the UNCRC states that children and young people have the right to say what they think should happen when adults are making decisions that affect them and to have their opinions taken into account. Critics argue that the Convention does not take into account the child's naivety, the social contexts in which they live and in which their rights have to be realised (Reynaert, Bouverne-de-Bie, & Vandevelde, 2009).

In reality it is parents who act as guides and decision makers for their child although this can be in conflict with the child's view. The autonomy of the child has been challenged by parents, for example the high profile case of the Gillick judgment or Fraser ruling (Gillick v West Norfolk and Wisbech Area Health Authority, 1985). Although the law has progressed since that ruling, there are still times when parents' decisions and desires and the child's rights come into conflict. Health and social care professionals are required to act in the child's best interests, and while the child's rights can and should be respected, the extent of the child's autonomy in any given situation can be difficult to determine.

The rights of children have been and still are influential in the domain of both child welfare practice and policy in the UK. Melton (2005) proposes that the UNCRC has been and continues to be a transformative instrument in guiding policy and informing the way in which policy makers and others have started to think about children's rights and agency. In the UK, legislation in the form of the *Children Act* (1989, 2004) and recently in England and Wales, the *Children and Social Work Act* (2017), sets out child rights and their welfare.

Child health policy and guidance: Where have we come from and where are we now for children?

In the UK, over the past twenty years many different policy initiatives have been implemented to shape services to more effectively address the needs of children and their families. The Kings Fund (Bayliss, 2017) have highlighted that improving children's lives requires policy action beyond that which can be achieved through clinical and care services. Examples of wide-reaching and comprehensive policies that capture the wider dimensions of children's lives include those proposed by non-governmental organizations; some examples are Barnardo's (Smith, 2017) work on mental health, and the Joseph Rowntree Foundation (Barnard, 2018) work on poverty in Wales.

Promoting children's health

Unhealthy children grow up to be unhealthy adults. Poor health and low income are connected, and as a consequence, both poverty and poor health make considerable demands on public resources (Marmot & Allen, 2014). Promoting children's health is essential for improving the population's health, and policies that prevent children's health problems can be wise investments (Currie & Riechman, 2015). Across the UK the strategies for children's health are set out via four country specific health programmes. *Healthy Children, Transforming Child Health Information* (DH, 2016), *The Healthy Child Wales Programme* (Welsh Assembly Government, 2016), *Getting it Right for Every Child* (Scottish Executive, 2017), and *Every Healthy Child Counts, Child Health Promotion* (Department of Health Social Services and Public Safety, (DHSSPS) 2016). However, the adequacy of support for these policies is questioned, as illustrated by a report from the Royal College of Nursing (RCN) (2018), *The Best Start: The Future of Children's Health*, which called upon the government in England to allocate sufficient resources to deliver the *Healthy Child Programme* and to make achieving the outcomes a key part of the government's social justice agenda.

An overview of integrated working and policy

The concept of professionals and cross boundary working has been advocated in policy provision. The *Every Child Matters* (ECM) agenda, a major influence during the period when the UK Labour Party was last in government, was introduced in 2003 by the Department for Education and Skills (DfES, 2003). The five key outcomes of the ECM agenda for children were: enjoying and achieving; staying safe; being healthy; making a positive contribution; and achieving economic well-being. These outcomes were underpinned by a wide range of organisational reforms that intended to bring a greater focus on early intervention, universal service provision and joined-up working and service integration (DfES, 2003; DHSSPS 2006; Scottish Executive, 2005). The ECM agenda introduced the beginning of a thirteen year programme of service integration with partners including: health and social services, police authorities, and the private and voluntary sectors. Integrated working is paramount for children and their families with complex needs, particularly in the early days when children are in hospital and families are under considerable stress (Coleman, 2003).

The Children's Plan in England (Department for Children & Schools & Families, (DCFS, 2007) brought professionals together via interagency arrangements to support families during the formative years. Since then there has been a decade of reform. Other initiatives such as *Team Around the Child* advocate integrated service models of delivery, with a lead professional who has the principal role between all agencies involved in the team caring for the child and family (DCSF, 2008). Policies are particularly important for children with complex needs as early intervention to prevent problems escalating could minimise distress for the child and their rights to be free from harm.

The pitfalls of integrated working

Providing the foundations for high quality service provision across child services is important, and the challenge to deliver this was recognised by the government (Laming, 2003). However, Brown and White (2006) identified an absence of evidence about the positive impacts of integrated working, and the continuing challenge of connecting evidence and practice. From a similar viewpoint Oliver and Mooney (2010) state that there is an absence of evidence to support that integrated working has a positive outcome for children. Moving Lord Laming's original recommendations (DH, 2003) beyond the arena of child protection, to include universal (such as education) and preventative services (such as social care) for all children introduced conflicting dimensions into the ECM integrated service model.

The ECM model was illustrated using an ‘onion’ graphic, with each layer of an onion organically encompassing the next inner layer. This model represents service integration as four layers: inter-agency governance, integrated strategy, integrated processes, and integrated frontline ‘delivery’ wrapped around outcomes for children, young people, families and community. It has been argued that the ECM agenda was structurally complex and difficult for professionals at delivery level (O’Brien, Bachmann, Jones, Reading, Thoburn, Husbands, Shreeve, & Watson, 2009). I can concur with this argument as my experience of integrated working in clinical practice is one in which I have experienced difficulties with communication between services, and where sharing information and different local policy agendas have been a challenge; these experiences are not uncommon. It is argued that government structures and processes tend to fail children because of fragmented departments across government and agencies that operate conflicting policies (Corrigan, 2008). The ECM agenda aimed to improve life chances for children and family outcomes and to strengthen family resilience as a means of helping families to take responsibility for their own lives. However, in fifteen years since the introduction of ECM, the agenda has moved on.

Some examples of policies that followed on from the ECM agenda were *The Children’s Plan* (DH, 2007), and the *Child Health Promotion Programme* (DH, 2008) which promoted integrated working. *The Healthy Child Programme* (DH, 2009) and more recently *Working Together to Safeguard Children* (HM, 2018) have reinforced the need for child-centred and co-ordinated approaches to keeping children safe and healthy through early preventive action.

Children with complex health care needs: policy and guidance

Government policy has tended to focus more generically on engagement with children, children’s rights and providing children with access to good services.

Less attention had been paid to children with complex health care needs; despite it being fundamental that the services children with complex care needs receive are as good as the services their peers without additional needs receive. Pinney (2016) argues that there is a widespread lack of awareness and policy attention, locally and nationally, on the rising numbers of disabled children with complex needs and life-limiting conditions. The concept of complexity of need involves the presence of a number of components, dimensions or factors that can vary in their nature, severity and chronicity; broadly speaking the term 'complex needs' encompasses children and adults who have "multiple inter-connected needs that span medical and social issues" (Rankin & Regan, 2004, p6).

There has been a steady increase in children who are born with complex medical conditions (D'Amore, Broster, & Le Fort, 2010; Milligan, 2010). The lack of standardisation of the different categories and definitions of children with disabilities or complex needs makes it difficult to aggregate data and obtain reliable estimates of the numbers of children involved at national and global level (World Health Organization, 2012; Baxter, Brugha, Erskine, Scheurer, & Vos, 2015). For a long time children with complex needs and disability were invisible and stigmatised and were unable to participate in society (Woodgate, Edwards, & Ripat, 2012). In addition, there is a lack of specialist nursing input or particular additional training for parents of children with complex needs (Townsley, Watson, & Abbott, 2004). Parents have assumed a major health care role particularly in the home in caring for their child with complex needs (Kirk, 2001; Leiter, Krauss, & Anderson, 2004: Ward, Glass, & Ford, 2014); this role requires extraordinary physical, emotional, social and financial resources (Murphy, Christian, Caplin, & Young, 2007; Strunk, 2010).

Internationally, countries such as the USA have focused on care strategies for children with complex needs that are similar to the UK; these were personalised care, home care and reduced hospital stays (Viner-Brown, 2005; Nageswaran & Farel, 2007; Wang & Barnard, 2004). Key challenges that need to be addressed in policy for children with complex health care needs include co-ordinated care, access to services, sustaining care at home, respite care/short breaks, palliative care and effective discharge planning (including care packages). Although each of these individual elements overlaps with other elements, they have been considered separately within specific policy. However, charities such as Together for Short Lives considered these elements within their guidance (Widdas, McNarama, & Edwards, 2013) Parents of children with complex needs have experienced lack of support and communication, and stress; resulting from poor discharge planning (Noyes & Lewis, 2007), and shortfalls and co-ordination in service provision (Brooks, Bloomfield, Offredy, & Shaughnessy, 2013) and respite care (Doig, Mclennan, & Urichuk, 2009).

Brooks et al.'s (2013) study on the experiences of parents whose children had complex needs reports discontentment from parents about the services they receive, despite the policy goals of the NSF framework (DH, 2004) and *Healthy Lives, Brighter Futures* (DH, 2009), which both aimed to promote and enable services for these children. A major theme from this study was a lack of communication and co-ordination between services (Brook et al., 2013), which Heaton, Noyes, Sloper and Shah (2005) note can impact on parents' lives and their psychological and emotional well-being. The reality of delivering policy and meeting guidelines is not straight forward, and the difficulties encountered may be due to the lack of resources, skills, and attitudes (Hewitt-Taylor, 2005).

Continuity of care for children with complex health care needs is crucial however complex government policy may result in confusion for families at the point in which they engage with services. Furthermore, the policies and guidance on discharge planning, co-ordination of care, sustaining care at home, and respite/short breaks have been difficult for professionals to initiate into their practice. This has resulted in some instances were a failure to implement policy into practice highlights that children with complex needs in the UK are being regularly underserved. This is discussed further in the next section.

Effective discharge planning

Despite the complexity of their need, many children with multiple and interconnected needs want to live at home, go to school, spend time with their friends and participate in community activities with family and peers (Social Care Institute for Excellence, 2011). The expectation for children with complex needs is that they should be cared for at home (Kirk & Glendinning, 2004; Wang & Bernard, 2004; RCN, 2009). However, despite evidence that being at home is the most appropriate place for children with complex needs to receive long term care there are still problems and delays in children getting home from hospital (Carter, Bray, Sanders, Van Miert, Hunt, & Moore, 2016). Although not without its challenges, effective discharge planning and being at home eases the difficulties children with complex needs and their families experience when they are in hospital (Samwell, 2011). Other benefits of effective discharge planning include reduction in both hospital utilisation and the cost of care for children with complex care needs (Graham, Pemstein, & Palfrey, 2008; Hewitt-Taylor, 2012: Long, Cabral, & Garg, 2013).

However, despite the evidence of the benefits of children being cared for at home, discharge planning is not always effective. As far back as 2003 the Joseph Rowntree Foundation reported significant numbers of children and young people with complex health needs were spending unnecessarily long periods of time in hospital because inadequate resources in community-based services were preventing their discharge (Stalker, Carpenter, Phillips, Connors, Macdonald, & Erye, 2003). In 2007, complaints about discharge from hospital and co-ordination of care across all cohorts of patients were fifth in the top ten complaints about the NHS referred to the Health Care Commission (Healthcare Commission, 2007). Despite evidence that the discharge process for children with complex needs can be challenging (Brenner, Larkin, Hillard, & Cawley 2015; Noyes, Brenner, Fox, & Guerin, 2014), there is no overarching government policy on discharge planning for children with complex needs. Service providers as well as families of children with complex needs can be daunted by the tasks associated with the child being discharged (Lewis & Noyes, 2007).

Stephens (2005) and Samwell (2012) suggest that improvements are needed to make discharge more efficient and sensitive to a family’s needs. Although the *NSF Framework for Children, and Young People and Maternity Services,* (DH,

2004) has emphasized the importance of discharge planning for children with complex needs, most of the guidance either comes from non-governmental organisations and research. Guidance includes the Council for Disabled Children’s framework for professionals negotiating and planning discharge for children with complex needs (Carlin, 2010), and the Barnardo’s report on planning discharge for children on LTV (Noyes & Lewis, 2005). However good these reports are, professionals are reliant on research that is over ten years old to guide their practice on discharge planning. Although this guidance is likely to have sustained its relevance, contemporary research would be useful to determine what, if any, gaps exist in this current evidence base. Other guidance from professionals about discharge planning for children with complex care needs advocates that key workers should implement the process (Lewis & Noyes, 2007).

Within the process of discharge planning for children with complex needs the planning and funding of complex care packages needs to be considered, and this process can be problematic, resulting in the children’s and families’ needs not being met (Stalker et al., 2003). Unlike other aspects of discharge planning there has been an abundance of frameworks and guidance delivered to professionals and commissioners of services with regards to funding processes (DH, 2004; DH, 2006; DH, 2007; DH, 2010). The most recent policy document, the *National Framework for Children and Young People’s Continuing Care* (2016), states that commissioners have a responsibility for ensuring that a robust process is in place for assessing, deciding and agreeing continuing care for children with complex needs. Services such as health and social care are jointly responsible for funding care packages The *Children and Families Act* (2014) imposes a range of duties in relation to providing better services, including co-operation between services such as health and social care and an obligation for joint commissioning arrangements to be in place in every area. The continuing care framework states that arrangements to deliver the package of care should be in place “as soon as possible”, (DH, 2016) however this can be problematic because of budget cuts to NHS and social care funding, causing time constraints in getting care packages up and running (Pinney, 2016).

Given that there is still no overarching policy on discharge planning for children with complex needs, the challenges that professionals and parents face are multifaceted. My own experiences of discharge planning are that it is time consuming. I cannot utilise a single pathway for discharge, as each area within the vast catchment area I serve has its own processes and pathways. Planning and providing the transition from hospital to home effectively is much more than passing on responsibility from one service to another; it is about building trust and creating long term relationships, ensuring that children, their families and professionals can work in partnership. Care co-ordination is vital and a wide range of input from different professionals for children with complex health needs is often required.

Co-ordinated care

Care co-ordination is a process that links children with complex needs and their families to services and resources in a co-ordinated effort to maximize the potential of children and provide them with optimal care. Care co-ordination requires an investment of dedicated time and the resources to develop, implement, and evaluate the processes and activities that comprise comprehensive, co-ordinated and compassionate care (Safriet, 2011). The problems are not just UK-based as there are reports that health care systems in Europe have struggled with inadequate co-ordination of care for people with chronic conditions (Ouwens, Wollersheim, Hernens, Huschler, & Grol, 2005).

More than a decade ago the *NSF Framework for Children, Young People and Maternity Services,* Standard 8 (DH, 2004) for disabled children and young people with a complex condition stated that they should receive co-ordinated care, high-quality child and family-centered services. This care should be based on assessed needs, promoting social inclusion and where possible enabling them and their families to live ordinary lives. One of the key markers within Standard 8 of the NSF is that disabled children, young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services. Three years after the publication of the

NSF, the government published *Aiming High for Disabled Children* (DfES, 2007) to specifically address the needs of children with complex needs and focus on access to and the availability of key services and the provision of seamless high quality services. Not long after this the Northern Ireland Assembly (DHSSPS, 2009) developed an integrated pathway for children with complex health care needs which guides community services in meeting the needs of this group of children and their families, stating that they will receive high quality co-ordinated care based on managing the risks to life.

More recently the National Institute for Clinical Excellence (NICE, 2017) produced a guideline that aims not only to involve children and young people with complex health care needs and their families in decisions about their care, but also to improve the support that is available to them throughout their lives. Guidance on co-ordinated care for children with complex needs has also come from the Council for Disabled Children's report, *Understanding the needs of disabled children with complex needs or life limiting needs* (Pinney, 2016), which presents a full picture on how to improve the planning of care, commissioning and policy development. The reality of caring for a child with complex needs (especially at home) is daunting for parents, not least because of the challenges of having to navigate complex-care services, often with little support.

The role of care co-ordinators has been key in providing support to families with complex needs at home (Taylor, Lizzi, Marx, Chilkatowsky, Trachtenberg, & Ogle, 2013: Howitt, 2011; Sloper, Greeco, Beecham, & Webb, 2006). However, progress towards achieving care co-ordination has been slow due to poor communication and identifying care co-ordinators (Parker, Spiers, Gridley, Atkin, Birks, Lowson, & Light, 2013). Charities such as WellChild are supporting increased numbers of families with the aim of giving children with complex needs the best possible chance to thrive safely and properly supported at home (WellChild, 2017). However, despite evidence that suggests that the role of the key worker is pivotal in ensuring that care needs are sustained, more needs to be done to improve services for continued care at home (Parker at al., 2013).

Sustaining care at home

Although there is generally greater awareness that whenever possible children with complex needs should be cared for at home this can only be sustained if there are adequate Children's Community Nursing (CCN) services to provide nursing care, support, education and training to children and families with complex needs. Two reports, *NHS at Home: Children's Community Nursing Services* (DH, 2011), and *A Healthy Life, Brighter Futures* (DH, 2009), have recognized the central role that CCN services play in the lives of children with disabilities and those with complex health needs. Within these reports there are clear expectations that commissioners should develop CCN services to provide care packages that cover 24 hours a day, seven days a week, including end-of-life care in the location preferred by the family. The Royal College of Nursing (RCN, 2009) proposes that CCN teams are at the heart of integrated care at home and that every child and young person has the right to expect this.

However, many children with complex needs do not have proper access to a community children's nurse due to the complexities in ensuring the availability of CCN practice (Kirk & Glendinning, 2004; RCN, 2009). Carter and Coad (2009) advocate that services in the community need to be sustainable and flexible, but the challenges of rising patient expectations and the increased number of children requiring community care create challenges to existing service provision. *The NHS at Home: Community Children's Nursing Services* (DH, 2011) reports that there are few local community nursing services that are able to meet the needs of children with life-limiting and life-threatening illness. More recently the national children's charity WellChild (2015) has called for greater investment in community children's nurses in order to support and improve the care for children and young people with long-term complex care needs and their families.

Short breaks / respite care

Considering the pressure that parents and CCN services are under to deliver care, the need for short breaks/respite care for children and their families becomes a critical issue. Although sometimes seen as separate provisions, respite and short breaks will be discussed together in this section as the purpose of most services for children with complex health care needs is to provide a break which is a positive experience for the child or young person when a carer needs a rest from their caring responsibilities (Crammer & Carlin, 2008). The charitable organisation Together for Short Lives states that short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child, or may offer care solely for the child or young person. Access for families whose children have complex needs to respite and short break services can range from a couple of hours to several days. The *Children's and Young Persons Act* (2008) states that individuals who provide care for disabled children should be given breaks from caring so that they can continue to care and do so more effectively (Carlin & Crammer, 2008).

The parliamentary hearing in October 2006 on services for disabled children found overwhelming evidence about the positive impact of short breaks for families with disabled children. The hearing identified the lack of access to these services as the single biggest cause of unhappiness with service provision for families with disabled children. Evidence shows that the extra support that is available from the provision of short breaks/respite care in the home or community can positively impact on the health and well-being of family members and their child with complex needs (International Children Palliative Care Network, 2008). However, some studies have found that respite care is not always positive and can be a distressing experience because of concerns about care delivery and poor facilities (Gilmour, 2002), while some parents experience guilt when leaving their child (Hartery & Wells, 2003).

Short breaks/respite care became a key element of government policy through the *Aiming High for Disabled Children* (DFES, 2007) agenda, which identified these services as the highest priority for families with disabled children. In December 2007, 21 Local Authorities were selected by a competitive process to serve as 'Pathfinders' to spearhead the effort to improve short breaks service delivery. During the period 2008 - 2011 there were huge investments in short breaks for children, with the government investing £370 million (DFES, 2007). In particular the Scottish government's *Community Care Circular guidance on short* *breaks* (2008) provided guidance on short breaks/respite care to assist partnership working between health and social care to meet their responsibilities to plan and deliver these services.

The short break partnership (North, 2015) was a one-year initiative led by Contact a Family as part of a consortium that included the Council for Disabled Children, Action for Children, and Kids, which was designed to provide guidance on the importance of short breaks for children and young people. However, it is often the case that short breaks are not accessible due to funding cuts and closure of respite services. The closure of the Nascott Lawn Respite Centre by the local Clinical Commissioning Group is a contemporary example of the retraction of respite services for children (Berry, 2017). Broach and Rook (2015) argue that Clinical Commissioning Groups and local authorities need to be challenged on these issues. Although there are pockets of good practice (Welsh, Dyer, Fereday, et al., 2014) in delivering short breaks and respite care there are still challenges to providing effective services.

Palliative care

Some children with complex health care needs may require palliative care for life-limiting conditions (Fraser, Miller, Hain, Norman, Alderidge, McKinney, Parslow, 2012), and a children's palliative care philosophy should inform their nursing care and other interventions because of their complex and unpredictable health care needs. Due to a lack of co-ordinated and joined-up working, the Department of Health in 2005 produced a framework for planning and commissioning palliative care (DH, 2005). A year later, in 2006 - 2007, the Department of Health in England (Craft & Killen, 2007) and their counterparts in Scotland (Audit Scotland, 2008) and Wales (Sugar, 2008) instructed an independent review of palliative care services for children and young people. These reviews overwhelmingly concluded that services had developed in a sporadic and unplanned way, and that funding for this patient group was often short-term. However, guidance on palliative care is now more firmly established, as can be seen for Scotland's *Strategic Framework for Action on Palliative and End of Life Care* (Scottish Children & Young People Palliative Care Executive Group, 2012), and in the *End* *of Life Care for Infants, Children and Young People: Planning and Management Guidelines* published in England by the National Institute of Clinical Excellence (2016). An aim of these guidelines is to involve children and families in decisions about their care and provided ongoing support throughout their lives.

Charitable organisations such as Together for Short Lives also provide guidance and support to families of children who require palliative care. Together for Short Lives advocates a core care pathway for children with life-limiting conditions (Widdas, McNarama, & Edwards, 2013). The pathway is guided by standards at each stage of the child's journey, underpinned by a series of goals and guides for professionals to support these families (including psychological support) in a staged approach. Within stage one, diagnosis or recognition is discussed, and this discussion includes a prognosis and liaison between hospital and community services. Stage two focuses on ongoing care including multi-disciplinary assessments and care planning. Stage three looks at end-of-life, planning end of-life care and bereavement support. The standards set down the level and quality of care that every family should expect during their journey. However, a 2013 study on evidence based planning and the costs of palliative care services in Wales concluded that there were important gaps in service provision; worryingly half of the children in the study locality did not have access to palliative care (Noyes, Edwards, Hasting, Hain, Toskita, Bennett, Hobson, Davies, Humphreys, Devin Spencer, & Lewis, 2013).

Children with tracheostomies: clinical guidance and care pathways

Turning more specifically to the needs of children with tracheostomies, this section now focuses on the guidance and pathways that aim to meet their needs. The care of a child with a tracheostomy requires a highly skilled health care team to deliver high quality care to the child and the knowledge and expertise around tracheostomy care to their parents. A clinical pathway is one of the main tools used to standardise care processes as a means of managing the quality of healthcare (Kinsman, Rotter, James Snow, & Willis, 2010). Individual hospitals have produced their own clinical guidance and pathways for children with a tracheostomy. For example, both Great Ormond Street Hospital, (GOSH, 2015) and Alder Hey Children's Hospital (2016) in the UK have produced clinical pathways. Cincinnati Children's Hospital in the USA is well-recognised for its online clinical pathway and best evidence statement (Cincinnati Children's Hospital, 2011), and its tracheostomy care handbook with videos (Cincinnati Children's Hospital, 2015) for professionals and parents to follow.

Wide variations in tracheostomy management have been reported to exist between hospitals as well as across community settings (Shah, Lander, Berry, Nussenbaum, Merati, & Roberson, 2012; Zhu, Das, Brereton, Roberson, & Shah, 2012), and these variations were drivers for the development of international and national guidelines for the clinical care of children with tracheostomies. In the USA, the Global Tracheostomy Collaborative (GTC) was formed in 2014 to improve the care and safety of children with tracheostomies (Lavin, Shah, Greenlick, Gaudreau, & Bedwell, 2014). The GTC consists of a multi-disciplinary group of providers, patients and families working to delineate and disseminate best practice surrounding tracheostomy care. One of the key drivers was the goal to develop best practice and standardization of care by prospectively collecting data on a large scale via international multi-institutional databases, which will eventually allow benchmarks to be set and quality improvement initiatives to be identified.

In the UK a best practice statement, *Caring for the child/young person with a tracheostomy* was developed in Scotland (NHS Quality Improvement, 2008), which sets out clinical guidance for caring for a child or young person with a tracheostomy. More recently the 'National Safety Project' has collaborated widely with key stakeholders in the UK to develop paediatric tracheostomy care and guidance that is support by local algorithms and podcasts (McGrath & Dougherty, 2016). These initiatives are intended to guide practice and promote a consistent cohesive and achievable approach to tracheostomy care. However, despite the guidelines available variations in care are common and something that I have often encountered in clinical practice.

Looking at all of these pathways and guidance, what is absolutely clear is that they are focused on a process of achieving clinical care in relation to tracheostomy management, management of risk and maintaining the safety of tracheostomies. However, none of these pathways or guidance encompasses the wider needs of the child and family, which could be included if they were developed within a model of children's nursing such as family-centered care. This would allow professionals to look at the holistic needs of children and families and not just the clinical management of the child's tracheostomy.

Despite careful searching there does not appear in the UK to be any government policy (not even a section within a policy on complex care or integrated or resilience models) about the care of children with a tracheostomies.

Conclusion of the policies, national guidelines and context of children's health and social care

Some important policy, guidelines and frameworks exist to support the delivery of children's health and social care. However, in the current climate, the resources required to ensure effective delivery such as sufficient staff and adequate technology, are often unavailable. Challenges to good care delivery within clinical practice arise from lack of funding, guidelines not being interpreted correctly or the complexity of implementing policy. It is widely accepted that although some polices and guidelines fail, others can have a positive impact on health and social care for children. For too long children with complex health care needs were apparently invisible to policy makers and their needs were not addressed. With the advent of clear policies about the requirement to meet the needs of children with complex needs, what is needed now is effective funding and support of these policies so that they become effective drivers of positive change for children and their families.

Organisation of the thesis

An explanation of the overall structure of my thesis completes chapter one. This provides an explanation of the content, chapters, bibliography, appendices and glossary of terms. The beginning of chapter one has already provided the reader with an overview and direction of my study.

Chapter two details the narrative literature review. The literature review draws on research on 1) the care-giving experiences of parents whose children have a tracheostomy but who do not need long-term ventilation, 2) children with a tracheostomy who do need long-term ventilation and, 3) children with complex respiratory needs, some of whom have a tracheostomy. The review also examines the literature on health professionals' experiences of caring for the same cohort of children and their families. The chapter concludes with a summary of the findings from the review, detailing any gaps in knowledge and identifying the main aims and the research questions of the current study.

In my third chapter, I aim to set out my paradigmatic position by stating the ontological, epistemological and methodological beliefs and approach that underpinned my study. I will explore how this study was positioned within the constructivist paradigm. I discuss how narrative inquiry is central to my study. This chapter outlines the study by detailing sampling, recruitment, and how the narrative interviews were undertaken. I also consider the ethical issues of the study and how they were dealt with**.** I address the quality of my study and I draw on the notion of goodness. I aim to make clear how I dealt with the parents' stories as data and the various approaches to my data that I considered and the ones I eventually applied. I provide a section on reflexivity for the reader to see my own journey and the story of my experiences of being a nurse practitioner/researcher and how I separated these roles. I also reflect on my journey as a novice researcher and the learning I acquired along the way.

In chapter four, I present the vignettes of the families in this study. These vignettes will allow the reader a unique insight into the lives of the families in this study and introduce the reader to the parents and to their children. These vignettes reveal how all their lives have changed because of the tracheostomy. These vignettes were composed from my field notes and they are presented in story form. The vignettes also aim to present an insight into the characters of the parents and their children.

The findings generated from the stories the parents shared with me are presented in chapter five. The findings offer the reader an overall meta-story, two core stories and six sub-stories. Due to the longitudinal aspect of my study these are presented at different stages of the parents' journeys. The meta-story broadly relates to narratives about parents' early and later experiences of having a child with a tracheostomy. The meta-story is composed of two core stories which are supported by six sub-stories. These sub-stories present elements of the parents' stories about their experiences on specific key events, exploring how parents found out that something was wrong with their child, the shock this brought and the realisation that a tracheostomy was needed. The sub-stories also present parents' feelings about seeing a difference in their child, living with their child's tracheostomy and facing the future.

In chapter six, I present a theoretical review of resilience, which is the central concept of my thesis. The key literature on resilience is presented, and related concepts in which resilience is defined and the origins of resilience research are discussed, showing how these influence the ways in which resilience is studied.

In chapter seven, I discuss the findings referring to resilience theory and the ABC-X model of parental resilience which explains a process of reframing. I summarise the parents' stories using the domains of my model with a focus on risk, protective factors and the parents' responses. The chapter focuses on how resilience (described in terms of four components): A- Levels of risk, B- Resources, C- Cognition, X- a process of reframing, is a central concept for understanding parents' experiences, and presents an argument about how resilience makes reframing possible. The thesis ends by drawing conclusions, indicating the limitations of the study and presenting both the implications for practice and the recommendations for future research.

Conclusion

This chapter has positioned me as a clinician and researcher and highlighted those aspects of my practice that drove me to undertake this study. I have presented an overview of the background to the procedure of tracheostomy, models of children nursing, and children’s health and social care policy, and have outlined the key challenges of parenting a child with a tracheostomy. I have presented a summary of the structure of the thesis.

In the next chapter, I present the literature review that enabled me to explore the existing published research and develop the proposed study.

CHAPTER 2: LITERATURE REVIEW

Introduction

In this chapter, I will present a narrative review and a critical examination of the literature that relates to the views and experiences of parents and health professionals providing care for children who have a tracheostomy. As children with a tracheostomy are frequently included in papers which examine children with complex respiratory conditions and long-term ventilation (LTV), this wider literature will be included in the review to add to the current understanding of parents' experiences of living with and caring for their child's tracheostomy. In this review, I will also present health professionals' views and experiences of caring for these children and their families. Inclusion of these different perspectives allows a greater range of experiences about caring for a child with a tracheostomy to be considered and contextualised. This narrative review will evaluate and appraise the literature in this field, and identify the gaps in the evidence and how this appraisal informed the rationale for the research that was conducted.

Narrative reviews

Narrative reviews provide a holistic overview or traditional review that critically appraises and summarises the literature which is relevant to the appropriate topic of interest (Hemingway & Brereton, 2009). A good quality narrative review has an objective focus that identifies and examines the significant literature based on certain criteria, such as studies published within a time-limited period (Shank & Villella, 2004). Henry, Skinningsrud, Viske, Przemyslawa, Walocha, Marouse, Shane-Tubbs, and Tomaszewski, (2018) discusses how the quality of narrative reviews can be increased by performing a comprehensive search and providing a clear list of databases. Readers of the review will rely on the expertise of the authors, and in turn, their expert evaluation of the methodological reliability of the sources from which their data was obtained and conclusions were drawn (Henry et al., 2018).

When discussing theory and different perspectives, narrative reviews can generate thought and debate. Narrative reviews must present the strengths and limitations of studies, and I have had to think critically and evaluate the studies in this review (Green, Johnson, & Adams, 2006). Narrative literature reviews should include critical data appraisal and data synthesis. However, this can differ according to the review's scope and methodology (Pare, Trudel, Jaana, & Kitsiou, 2015). While some narrative reviews focus on breadth as opposed to depth of literature**,** critical appraisal of the methods used by individual studies can improve reliability (Grant & Booth, 2009).

Unlike systematic reviews that benefit from guidelines such as the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses; Moher, Liberati, Tetzlaff, & Altman, 2009) statement, there are no acknowledged guidelines for narrative reviews, and this can be seen as a limitation (Pautasso, 2013). There are disadvantages to narrative reviews such as little explicit structure for gathering and presenting evidence, and researchers co-ordinate how they search for relevant research articles, what they include, how they consider the results, and what conclusions to draw upon (Collins & Fauser, 2005). Information is collected and interpreted unsystematically, with subjective summaries of findings. Validity and balance depend mainly on the integrity of the researcher and the diligence of peer reviewers and editors (Fletcher & Fletcher, 1997). Despite these disadvantages, narrative reviews remain frequent within the literature, as they offer breadth of literature coverage and the flexibility to deal with evolving knowledge and concepts (Collins & Fauser, 2005).

A decision to undertake a narrative review in the study reported in this thesis could be criticised as it is arguably a less robust approach to reviewing the literature than undertaking a systematic review (also see p258). A systematic review could have provided a more structured and more systematic approach to the literature**.** However, when originally considering the literature available it was clear that a systematic review would have been inappropriate as most of the literature was itself insufficiently robust**.** However, a robust process was followed in searching and identifying the evidence, and each of the papers was critically evaluated to decide their inclusion /exclusion (see table 4 a, b, c and Appendix 1). This narrative literature review has been peer reviewed and published in the International Journal of Pediatric Otorhinolaryngology (Flynn, Carter, Bray & Donne, 2013).

Literature review

This critical review of the literature is structured around two sections. In the first section, I set out the aims and objectives of the review, how the search strategy was applied, the critical appraisal of the literature in this field and identify the gaps in the evidence. In the second section, I examine and synthesise the reported experiences with a particular focus on care giving, and social care and service delivery. Within the literature, the papers considering children with a tracheostomy tend to focus on three groups:

1. Children who have a tracheostomy but who do not need long-term ventilation.
2. Children with a tracheostomy who do need long-term ventilation.
3. Children with complex respiratory needs some of whom have a tracheostomy.

Although these three groups of children are likely to have different levels of intensity of medical need, for the purpose of this review they are not presented separately. This is because although they experience slightly different situations, the main issues reported by parents and professionals across the three groups are shared. In the first iteration of reporting the review, the groups were considered separately but this resulted in considerable repetition and the synthesis was less coherent. However, it is accepted that presenting these diverse groups together could result in a review which homogenises experiences, so care has been taken to ensure that differences as well as commonalities are reported. Where a finding is specific to one particular group of children, for example, those requiring long-term ventilation, this will be made clear.

The narrative review is structured under four main themes and their associated sub themes.

1. Caregiving experiences of parents
    Sub themes: ‘caring’, ‘coping’, ‘negotiation of care’ and ‘time’.
2. Social experiences of parents
    Sub themes: ‘social isolation’ and ‘quality of life’
3. Parents’ experiences of service organisation and delivery of care
    Sub themes: ‘parents as experts’, ‘care packages’ and ‘support’.
4. Caregiving experiences of health professionals
    Sub themes: ‘providing supportive health care’ and ‘education and information’.

Aims and objectives

The aim was that the findings of the narrative review would examine parents’ and health professionals’ views of having a child and the caregiving role for a child with a tracheostomy to help inform the current research study. The objectives of the review were to identify from the literature:

1. Parents’ views and experiences of having a child who has a tracheostomy.
2. Parents’ views and experiences of having a child with complex respiratory needs and who are on LTV.
3. Health professionals’ roles in caring for children who have complex respiratory needs and who are on LTV or have a tracheostomy.
4. The methodological limitations of current approaches to studying parents’ and health professionals’ views and experiences of caring for children with a tracheostomy, complex needs and on LTV.

In the next section, I present my search strategy, critical appraisal of the literature and the quality of the papers in the review.

Search strategy

The literature search was comprehensive and aimed to identify publications concerned with the views and experiences of parents and professionals of children with a tracheostomy, with complex respiratory needs and who are on LTV. Key databases were searched using key words, Medical Subject Headings (MeSH) terms and Boolean operators (see Table 1). The databases were selected on the basis that they could support a comprehensive and in-depth search into the health and social care literature. Inevitably, there will have been an evolution in clinical practice over time so a decision was made for literature to be searched from 1990 onwards. At this time point there were changes to the developments in tracheostomy tube design and in the planning and the teaching of clinical skills and delivery of health care to children with a tracheostomy and their families (Carron, Derkay, & Strope, 2000). The experiences of parents after 1990 are likely to be different from parents before 1990.

Figure 1 presents a flow chart of the numbers of papers identified, screened and found to be eligible for inclusion in the review. The searches identified 522 citations (1990 - 2014) and a further 307 (2014 - 2017) and these were reviewed and, if relevant, the abstracts were evaluated. Clear inclusion and exclusion criteria were identified (Table 2).

Table 1: Literature Search Strategy

Databases searched
- Academic Search Elite
- CINAHL PLUS (Cumulative Index to Nursing and Allied Health Literature)
- MEDLINE
- PsycINFO
- Embase
- Proquest

Years covered by the search
- 1st Jan 1990- 31st July 2014
- Revisited from 1st August 2014- 22nd August 2017.

Search terms
- Parent* OR Mother* OR Father*OR Care* OR Health Professional*
  AND
- Tracheotom* OR Tracheostom* OR LTV* OR Complex Needs*OR Respiratory
  AND
- View* OR experience* OR perspective*
  AND
- Child* OR Infant* OR Adolescen* OR Baby OR Teenager OR Paediatric OR Pediatric

MeSH terms
- Parental attitudes, Medically fragile, Caregiver burden.

Papers were excluded if the abstracts revealed that they did not fit the inclusion criteria, for example, Wilfond's (2014) paper was an expert commentary piece on decision-making on ventilation of children with profound disabilities as opposed to an empirical study. The key reasons for excluding papers were that the papers were found to be publications about various clinical procedures relating to tracheostomies (e.g. surgical and dilation techniques, complications of surgical procedures, outcomes of ventilation weaning or indications for performing tracheostomies). This search stage resulted in a very large number of duplicates, and in hindsight revisiting the search terms may have been beneficial to reduce this; however, on reflection, this was part of my learning journey. At the end of the review of 208 abstracts, 84 full papers were obtained. In addition to the database search, I checked the reference list of all relevant articles to try to identify any further articles that would be suitable for the review. This resulted in two more papers being identified, resulting in 86 papers being screened for abstract relevance using the inclusion and exclusion criteria (see Table 2). After assessment for relevance, this left 42 full papers that were suitable for further review. Some papers reported the views of parents and children or siblings together. At the time of appraisal it was felt that these papers did not relate to the main aims and objectives of the review and were excluded; in hindsight, these papers may have added benefit to the review because there were some parental views reported.

Table 2: Inclusion and exclusion criteria

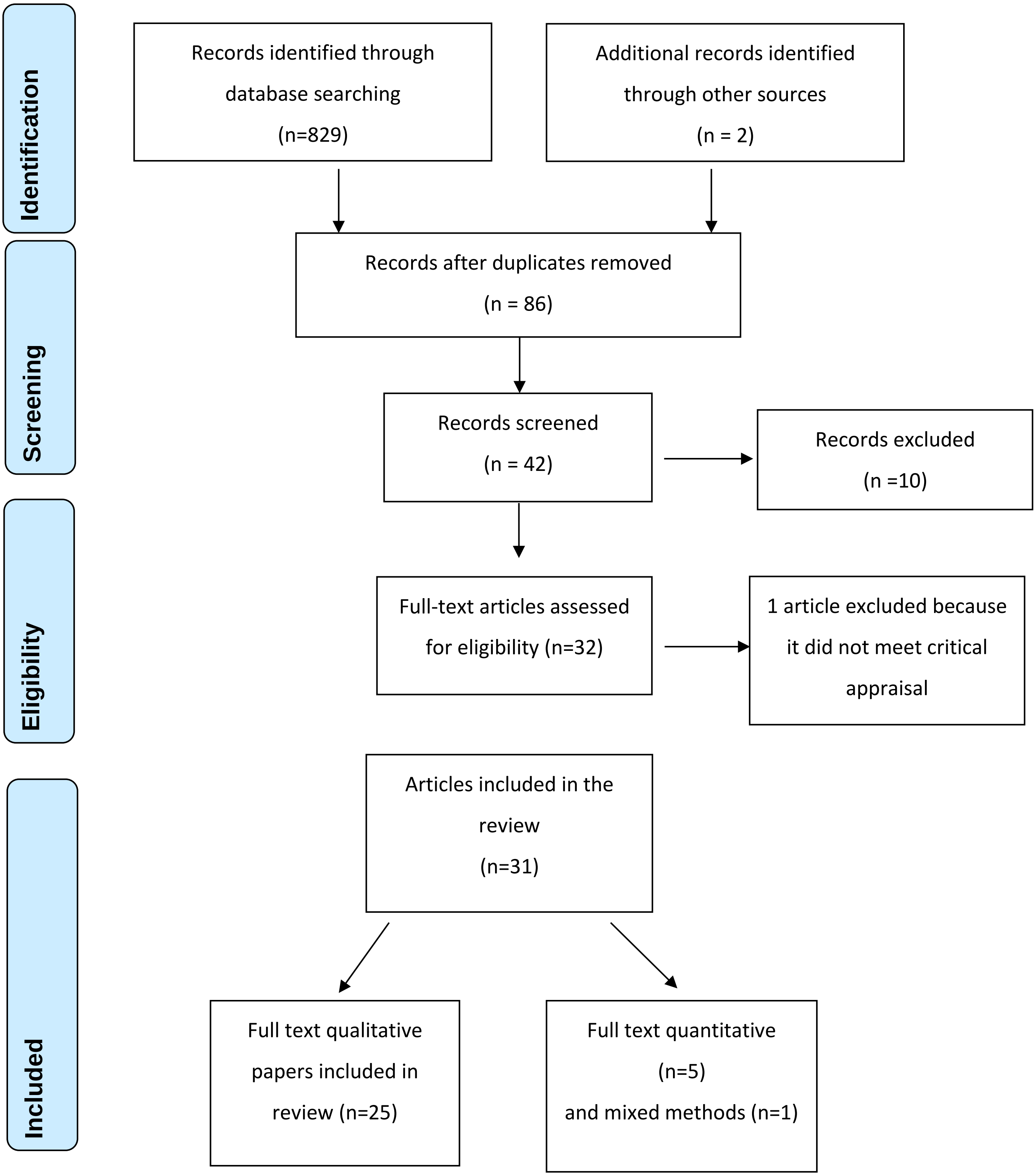
Inclusion

- Studies that reported empirical research (qualitative or quantitative) relating to the aims and objectives of the review.
- Published between 1st Jan 1990 and 22nd August 2017.

Exclusion

- Studies of adults (even if parents' views were sought)
- Studies that included children's or sibling's views (even if parents' views were sought)
- Literature reviews
- Expert commentaries
- Not published in the English language

Figure 2.1: Flow chart for identification and selection of included articles.



Full papers were screened for relevance; the excluded articles along with a rationale are presented in Table 3.

Table 3: List of the excluded articles

List of the 10 excluded articles.	
Exclusion criterion	**Articles excluded**
Studies that did not seek parents' or health professionals' experiences or views of the caring role	Messineo et al., (1995); Graf et al., (2008); Hewitt-Taylor., (2008b); Day et al., (2009); Tibballs et al., (2009); Toly et al., (2012); Vanker et al., (2012); McDonald et al., (2015, 2017); Harnick et al., (2017).

Ten papers (Table 3) were excluded because they did not seek parents' or health professionals' views on caregiving for children with a tracheostomy, who are on LTV or who have a chronic respiratory condition. The focus for these papers was as follows: two papers, by the same authors, explored family carers who cared for children and adults (such as parents or spouses) and the findings of the study presented an amalgamation of (both adults' and childrens') views and it was unclear as to which view was being presented (McDonald, McKinlay, Keeling, & Levack, 2015, 2017). One paper assessed the impact of a family-centred care co-ordination programme on the quality of care received by children who had undergone a tracheostomy (Harnick, Diercks, Guzman, & Harnick, 2017). One paper looked at the depressive symptoms that mothers can acquire when their child is on LTV and did not consider the views and experiences of parents whose children have tracheostomies (Toly, Musil, & Carl, 2012). One paper addressed how to perform the skill of tracheal suction of children (Day et al., 2009). One reported parental views on the opportunity for play for children with a complex condition (Hewitt-Taylor, 2008), and another was an expert commentary on the opportunity for play for children with a complex health needs. Another study used children's past medical records to highlight the journey of discharge planning for children with tracheostomies but the data excluded parents' views (Graft, Montagnino, Hueckel, & McPherson, 2009). Other bodies of evidence looked at children on LTV and their support at home (Tibballs et al., 2009), the effectiveness of home programmes for children with tracheostomies (Vanker, et al., 2012), and safety issues for children with tracheostomies (Messineno et al., 1995). This left 32 full papers for critical appraisal review.

Critical appraisal

The critical appraisal process allowed careful examination of the 32 articles selected for full text appraisal, to judge their trustworthiness, value and relevance to the chosen context (Burls, 2009). All of the qualitative and quantitative papers have been appraised using tools from the Critical Appraisal Skills Programme (CASP). The CASP critical appraisal tools have been validated to ensure that the critical appraisal of studies occurs in a standardised way (Barker, 2014). Twenty-six papers using qualitative methodologies were assessed using the CASP qualitative appraisal tool (CASP, 2018 see Appendix 2). Five papers reporting quantitative approaches were appraised using the appraisal tool for cohort studies developed by the Critical Appraisal Skills Programme (CASP, 2010 see Appendix 2); the tool was chosen as it has the best fit to appraise the studies, which predominantly were questionnaire-based.

One paper using mixed methods was appraised using nine questions for assessing the integration of Mixed Methods studies using Good Reporting of Mixed Methods Study (GRAMMS) (O'Cathain, Murphy, & Nicholl, 2008, see Appendix 3), allowing me to explore the integration between quantitative and qualitative methods.

Smith, Williams and Gibbon's (2003) qualitative paper focusing on the experiences of parents and their child's carers in school was excluded from the review after appraisal as it was judged poor quality. This paper (Smith et al., 2003) only provided a brief explanation of the purpose of the questionnaire used in the study and there was no reference to its format (e.g. Likert scale or open-ended questions). Additionally, although the response rate was reported as being

100%, the authors noted that most of the questionnaires were not complete. The analytical process was not stated and was therefore unclear and this affected the reliability of the data. After the critical appraisal, thirty-one articles met the criteria for inclusion in the review. The next sections will present these in more detail.

Quality of studies

As part of the quality review process a table of the study characteristics was created to succinctly present the research aims, design and methods, sample size, overview of findings/results, and researcher comments (Appendix 1). A brief over view of the critical appraisal of the literature is presented in tables 4A, a more detailed critical appraisal table can be found in Appendix 1 (tables A,B, C).

Overall the quality of the qualitative studies was fairly robust; the key quality issues relate to poor reporting on the researcher-practitioner relationships and some studies lacked clarity about their recruitment process. Some qualitative studies were of good quality (Hobson & Noyes, 2011; Kirk et al., 2004; Kirk et al., 2005; Woodgate et al, 2012; Ward, 2015) and very relevant to the review. The quantitative studies mainly utilised validated measures of engagement, for example Montagnino and Mauricio (2004) used the Impact on Family Scale Crisis and the Oriented Personal Evaluation Scales. However, one study used a questionnaire that was specifically developed for their study (Cohen et al., 1998).

The quality review of the quantitative studies indicated that overall quality of the studies was reasonable and included some relevant studies on children and families with a tracheostomy that merited inclusion. Further detail on the quality of the studies included in the review can be found in the methodological quality section in this chapter (p76-77).

Table 4: Summary of the critical appraisal of the reporting of literature' (see Appendix 1, Tables A, B & C for greater detail).

	Type of study	Research focus	Recruitment	Data collection	Research bias	Ethical issues	Data analysis	Findings	Knowledge	Overall quality (score)
Berry et al., 2009	Qual	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟨	**Good (20)**
Brett, 2004	Qual	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**
Callans et al., 2016	Qual	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	**Good (23)**
Diehl et al.,1991	Qual	🟩	🟨	🟩	🟨	🟥	🟩	🟨	🟨	**Moderate (17)**
Cohen et al.,1998	Quant	🟩	🟩	🟩	🟨	🟨	🟩	🟩	🟩	**Good (22)**
Giambra et al., 2014	Qual	🟩	🟩	🟩	🟨	🟥	🟩	🟩	🟨	**Moderate (19)**
Giambra et al., 2017	Qual	🟩	🟩	🟩	🟨	🟨	🟩	🟩	🟨	**Good (21)**
Harnick et al.,2003	Quant	🟩	🟩	🟩	🟩	🟨	🟨	🟩	🟨	**Good (21)**
Hobson & Noyes, 2011	Qual	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**
Hopkins et al., 2008	Quant	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**
Kirk, 2001	Qual	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟩	**Good (23)**
Joseph et al., 2014	Quant	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩	**Good (23)**
Kirk & Glenndinning, 2002	Qual	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟩	**Good (23)**
Kirk et al., 2005	Qual	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**
Margolan et al., 2004	MM	🟩	🟨	🟩	🟩	🟥	🟩	🟨	🟨	**Moderate (18)**
Mentro & Steward, 2002	Qual	🟩	🟨	🟩	🟩	🟥	🟩	🟨	🟨	**Moderate (18)**
McNamara et al., 2009	Qual	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	**Good (23)**
Miller et al., 2009	Qual	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	**Good (23)**
Mendes et al.,2013	Qual	🟨	🟩	🟩	🟩	🟨	🟩	🟩	🟨	**Good (21)**
Mendes, 2016	Qual	🟨	🟩	🟩	🟩	🟨	🟩	🟩	🟨	**Good (21)**
Montagnino & Mauricio, 2004	Quant	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**
Noyes et al.,1999	Qual	🟨	🟩	🟩	🟩	🟨	🟩	🟩	🟨	**Good (21)**
O'Brien, 2001	Qual	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	**Good (23)**
O'Brien et al., 2002	Qual	🟩	🟨	🟩	🟩	🟨	🟨	🟨	🟨	**Moderate (19)**
Rehm & Bradley, 2005	Qual	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟩	**Good (23)**
Reeves et al., 2006	Qual	🟩	🟩	🟨	🟩	🟨	🟩	🟩	🟨	**Good (21)**
Smith et al., 2003	Quant	🟨	🟩	🟩	🟩	🟥	🟥	🟥	🟥	**Poor (11)**
Tomment, 2003	Qual	🟩	🟩	🟨	🟩	🟨	🟩	🟩	🟨	**Good (21)**
Wilson et al.,1998	Qual	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	**Good (23)**
Woodgate et al.,2012	Qual	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**
Ward et al.,2015	Qual	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	**Good (24)**

Key: **Traffic light system**: **Red**: (Score 0) Poor quality/reporting of evidence; **Amber**: (Score 2) Moderate quality /reporting of evidence: **Green**: (Score 3) Good quality of evidence. Overall quality 0-<15, poor quality; 15-<20, moderate quality; 20-24 good quality. Type of study: Qual – qualitative; Quant – quantitative; MM – mixed methods

Countries in the review

The literature reviewed includes an international body of research, representing experiences of a number of different health care systems. The majority of the research on children with tracheostomies originated in the USA (n=5) with the remainder from the UK (n=1) and New Zealand (n=1). The studies focussing on children with complex respiratory needs came from the UK (n=3), USA (n=3), Canada (n=2) and Australia (n=1); and literature on children on LTV from the USA (n=8), the UK (n=6), and Canada (n=2).

Participants

The participants in both the quantitative and qualitative studies in this review included a range of different stakeholders (see Table 6), with mothers' perspectives dominating the literature, as they often are (or are assumed to be) the primary caregiver (Wilson et al., 1998). Fathers' views are less frequently reported, with only one study focusing solely on fathers' views (Hobson & Noyes, 2011). It is difficult to ascertain in some studies who participated because it was simply reported that the families' primary care giver or 'parents' were the respondent to the questionnaire or interview (Cohen et al., 1998; Noyes et al., 1999; Harnick et al., 2003; Montagnino & Mauricio, 2004; Hopkins et al., 2009; Brett, 2004; Reeves et al., 2006; Rehm & Bradley 2005; Mah et al., 2008; Mendes, 2016; Giambra et al., 2017). Most studies seeking health professionals' views did not indicate participant's individual roles (Kirk, 2001; Kirk & Glendinning, 2002, 2004; Berry et al., 2011). However, two studies singled out the nursing role (Mendes, 2013; Giambra et al., 2017), with another stating that medical and allied health professionals took part (Ward et al., 2015).

Table 5: Type and numbers of participants identified by research design.

Numbers of participants across all studies			
	Number of participants involved in qualitative method studies N= 673	Number of participants involved in quantitative method studies N=297	Number of participants involved in mixed method studies N=15
Grandmothers	1	0	0
Mothers	230	67	13
Fathers	70	4	0
Parents	17	0	2
Families/caregivers	167	226	0
Health professionals	153	0	0
Nurses	35	0	0

When reviewing some studies there were unclear reporting practices when discussing groups of children in the study (Brett, 2004; Joseph et al., 2014). The challenge for me was to identify which children had a tracheostomy without needing LTV and which children had a tracheostomy and who were on LTV. The studies were unclear as to why they had grouped these cohorts of children together. A decision was made by myself that if parents of a child who was on LTV were recruited to the study the study was reported in the LTV section.

Methodological quality

The review identified seven studies on parents' views of having a child with tracheostomy, drawing on quantitative (n=4) and qualitative (n=3) data using questionnaires, semi-structured or structured interviews (Cohen et al., 1998; Harnick et al., 2003; Hopkins et al., 2008; Montagnino & Mauricio, 2004; McNamara et al., 2009; Berry et al., 2011; Callans et al., 2016). All of these seven studies' methodological approaches reflect a snapshot view of parents' experiences. Researchers may need to consider the process of change as an important aspect of the research study; especially if time has a significant impact on participants' experiences, then a single episode of data collection may not be sufficient (Ritchie & Lewis, 2003).

In the four quantitative studies reviewed, the data collection tools followed a structured set of questions, with some studies relying on questionnaires. Although, questionnaires provide a relatively cheap, quick and efficient way of obtaining large amounts of information from a large sample of people, the responses are fixed and there is less scope for respondents to supply answers, which reflect their true feelings on a topic (McLeod, 2014). Two of the questionnaires used were validated tools; the Pediatric Tracheotomy Health-Status Instrument (Hartnick, et al., 2002) and the Impact on Family Scale Crisis Oriented Personal Evaluation Scales (McCubbin, Olson, Larsen, Corcoran, & Fischer, 2000). Sample sizes varied between studies, with questionnaires in one study being completed by a sample size of 18 (Montagnino & Mauricio, 2004) and by 154 in another study (Harnick et al., 2003).

Only one study (from the UK) focused entirely on parents' experiences of having a child with a tracheostomy (Hopkins et al., 2008). The study reported important issues about parents' quality of life with a child who has had a tracheostomy**.** Although Hopkins sets the scene for further research, the study applied a very structured approach to the interview process. In a structured interview there is a complete script that is prepared beforehand, leaving no room for improvisation (Myers & Newman, 2007).

The three qualitative studies, which were conducted with a focus on children with tracheostomies, discussed parents' views on transition from hospital to home, health information and humidification techniques, and caregiving for their child with a tracheostomy (Callans et al., 2016; Berry et al., 2011; McNamara et al., 2009). The qualitative research which focuses on children who have a tracheostomy that met the objectives for this review had recruited only parents (twenty-eight females and ten males) (Callans et al., 2016; Berry et al., 2011; McNamara et al., 2008). None of the reported qualitative data on children with tracheostomies has been collected longitudinally.

Views and experiences of parents

In this section, the body of research considering parents' caregiving experiences provides evidence of three themes: the realities of providing care, social experiences, and experience of service organisation. These and their associated sub themes are discussed below within the following themes:

1. Parents' experiences of the realities of providing care
   Sub themes: 'managing caregiving' and 'negotiation of roles and the impact this has on being a parent'.
2. Social experiences of parents
   Sub themes: 'social isolation' and 'quality of life'
3. Parents' experiences of service organisation and delivery of care
   Sub themes: 'parents as experts', 'care packages' and 'support'.

Parents' experiences of the realities of providing care

In this section, I present how parents experienced the realities of the caregiving role and how this affected their everyday lives. These realities involved managing clinical procedures and the ways this tested parents, including the additional time this took, the negotiation of caregiving with professionals and a conflict of identities.

Managing caregiving

Seventeen studies explored parents' views about their caring role and the impact that this has on them and family life. These studies were conducted in the following countries UK (n=8), USA (n=7), Canada (n=1), and New Zealand (n=1) (see Table 4). Combined, these seventeen studies give 455 parental views on their caring role with strong commonalities of experience. It was clear that it is common for parents of children with complex conditions to provide care for their child at home. The literature suggests that this care sometimes involves highly technical medical and nursing procedures (Kirk, 2001; Kirk & Glendinning, 2002; Kirk & Glendinning, 2004; Kirk et al., 2005; Mendes, 2013), and often requires changes to be made to the home environment. This can result in the home becoming a medicalised space filled with equipment commonly found in hospital, such as oxygen cylinders, suction machines, ventilators and feeding pumps (O'Brien, 2001; Mah et al., 2008; Wilson et al., 1998; Kirk et al., 2005; Mendes, 2013).

Typically, parents described that performing clinical procedures on their child is distressing for all concerned (Kirk, 2001; Kirk et al., 2005; Margolan et al., 2004). Parents reported that they felt professionals disregarded the emotional aspects of caregiving and only focused on their acquisition of technical competencies (Kirk & Glendinning, 2004). Caring for a child with a tracheostomy and needing LTV has far-reaching effects on the caregiver, adversely affecting their health, emotional well-being, sleep, relationships and family life (Hopkins et al., 2008; Joseph et al., 2014). McNamara et al.'s (2009) study interviewed mothers of a child with a tracheostomy and noted that a frequent issue for them was exhaustion due to managing their child's care and the ensuing disrupted sleep. In addition, parents have talked about equipment being less efficient at home because different suction models had been supplied, which significantly affected their daily routine (Mah et al., 2008).

Some parents reported the psychological burden they experience when providing care for their child with a tracheostomy (Harnick et al., 2003; Montagnino & Mauricio, 2004). A study from the UK that sought parental experiences on caring for their child with a tracheostomy reported that some parents seem to cope with the clinical caring aspect with minimal impact on their life, while other parents seem to experience a daily struggle, which adversely affects their health, emotional well-being and family life (Hopkins et al., 2008). A consistent finding from parents whose child is on LTV is that their lives are often dominated by undertaking clinical procedures and this experience leads them to question whether they are a parent or a nurse (Kirk et al., 2001; Kirk & Glendinning, 2004; Reeves et al., 2006). Parents' roles in caregiving are reported as being multifaceted and involved managing their child's often unpredictable and complex medical condition, as well as organising home support services (Kirk et al., 2001). Parents caring for their child on LTV and with a tracheostomy have talked about how the rest of the family's needs become secondary priorities, as demands of caring for their child disrupts normal family routines (O'Brien, 2001; Kirk et al., 2005; Mah et al., 2008).

Making sure a child's airway with a tracheostomy is safe and secure is key to their survival. Throughout the literature parents commonly reported feeling worried and concerned about their child's safety, and how this could make them feel highly stressed (O'Brien & Wegner, 2002; Montagnino & Mauricio, 2004; Reeves et al., 2006; Hopkins et al., 2008; McNamara et al., 2009). McNamara et al., (2009, p192) built on the core concept of 'living worried' and the constant uncertainty for parents of a child who has a tracheostomy, which included worries about the present and the parental fears of 'what if' their child might die at night if unattended. These fears can lead to stress, and Joseph et al.'s, (2014) quantitative study used a cross-sectional correlational design to study parents who care for a child with a tracheostomy /LTV at home. This used the Family Inventory of Life Events Scale, Family Crisis Oriented Personal Evaluation Scale, and Psychological General Well-Being Index to measure parents' stress, coping, and quality of life. Findings from the study show that poor quality of life scores were associated with moderate stress and that better quality of life scores were associated with better coping scores and lower stress scores (Joseph et al., 2014).

Other qualitative studies have revealed that parents of children on LTV report that caregiving can cause them significant anxiety especially immediately following discharge home (Wilson et al., 1998; O'Brien, 2001; Mentro & Steward, 2002), reporting constant worry about their ability to successfully manage their child's tracheostomy care (Montagnino & Mauricio, 2004; McNamara et al., 2008). Wilson et al.'s, (1998, p230) study reported that mothers whose child is on LTV discussed how learning to be a mother and caregiver to their child was ongoing and the duality of the roles often created 'personal disunity'; for example, having to do chest compressions was necessary but also caused their child to suffer, which caused them internal discord. The groups of children in this literature review require an enormous amount of clinical care and often need additional support from nurses. Having nurses in the home freed mothers to focus on being a parent to their child (Wilson et al., 1998). Mothers highlighted that if this scheduled time as a mother was hindered due to them having to carry out clinical caregiving, it caused them unjustifiable distress.

Several studies reported the ‘constant worry’ parents felt about living with ‘uncertainty’, and this was evident in parents whose child required LTV (Wilson et al., 1998; O’Brien, 2001; Mah et al., 2008) as well as parents whose child did not need LTV (Mentro & Steward, 2002; McNarama et al., 2009; Callans et al., 2016). The primary concern for most parents was the ‘uncertainty’ and unstable situations surrounding the medical condition of their child (Wilson et al., 1998; O’Brien, 2001; Mentro & Steward, 2002; Mah et al., 2008; McNamara et al., 2009), and the disruption caused to the balance of their home life if their child’s medical condition was uncertain or deteriorated (Callans et al.,2016).

Several studies in the review report how parents are able to cope with their child’s caregiving. Ten studies explored parents’ experiences of coping, and of these nine are broadly qualitative in design, with only one study (Montagnino & Mauricio, 2004) adopting a quantitative approach (see Appendix 1). The literature reports that parents commonly experience the sense of not being able to cope with the caring role (Wilson et al., 1998; O’Brien, 2001; Kirk & Glendinning, 2002; Mentro & Steward, 2002; Brett, 2004; Montagnino & Mauricio, 2004; Rehm & Bradley, 2005, Mah et al., 2008; McNamara et al., 2009; Hobson & Noyes, 2011). Parents of children with a complex respiratory condition discuss how beneficial a supportive network of friends and family was in assisting with their coping abilities, as this decreased their isolation and gave them the opportunity to share their anxieties and loneliness (Mentro & Steward, 2002). Parents reported that having a positive sense of humour (O’Brien, 2001), spiritual help (Wilson et al., 1998; Montagnino & Mauricio, 2004) and routine (McNamara et al., 2009) were also useful coping strategies.

A frequently used strategy discussed by parents across all groups of children as helping them to cope was normalisation (Mentro & Steward, 2002; Rehm & Bradley, 2005; Mah et al., 2008; Hobson & Noyes, 2011; Callans et al., 2016). Knafl and Deatrick (2002) discuss how families of children with complex conditions use the process of normalisation, which allows them to consider what is normal to them in their current situation. Families of children with complex respiratory conditions can undergo major life changes that affect their family functioning, and understanding how families adjust to the challenges is important (O’Brien & Wegner, 2002). Rehm and

Bradley (2005) noted that many parents talked about how it was possible to have a good life even if it was not necessarily normal by usual standards, although Callans et al., (2016) note that in some cases parents found it difficult to achieve a new normal. One study which was unique because it focused on fathers' views described how striving for normality in their lives was central to them providing care to their child (Hobson & Noyes, 2011). Fathers reported guilty feelings when juggling their work and home lives, experiencing high levels of stress and difficulties coping with clinical care, whilst trying to maintain normality (Hobson & Noyes, 2011). Other studies have discussed how maintaining normalcy is used as a coping mechanism to maintain a routine and environment for medically fragile children with respiratory issues and children on LTV (Mentro & Steward, 2002; Mah et al., 2008). In Mentro and Steward's (2002) study, one parent discussed the importance of including everyday routines in their child's life, such as interactions with pets and siblings.

Studies using qualitative methods have offered some insights into how parents feel about caring for their child over an extended period of time (Wilson et al., 1998; Tommet, 2003; McNamara et al., 2009; Mentro & Steward, 2002). Some studies suggest that the care process grows easier over time due to parents' increasing confidence in their ability to deliver care (O'Brien, 2001; Tommet, 2003; Mah et al., 2008; Callans et al., 2017). Only one study that focused on medically fragile children has presented a perspective on family life and the processes that changed over time (Tommet, 2003). In Tommet's (2003) study, parents discussed the learning process associated with understanding the extent of their child's needs and the impact this had on their lives, enabling them to move from being passive observers in relation to their child's care to active participants. Some literature reveals that although confidence will develop over time for some parents, it never brings acceptance of their child's condition (Wilson et al., 1998; Montagnino & Mauricio, 2004).

Negotiation of roles and the impact this has on being a parent

All the literature on negotiation of care has been undertaken using qualitative methods. Studies from the UK (Kirk, 2001; Kirk & Glendinning; 2004; Reeves et al., 2006) and USA (Callans et al., 2014; Mendes, 2016; Giambra et al., 2014, 2017) have produced robust evidence on how difficulties over the negotiation of care can impact negatively on parents (total number of 106 parents, see Appendix 1). Negotiation of care refers to the process of nurses and parents discussing the level of care parents wish to be responsible for and then discussing plans for the child's care (Reeves et al., 2006). Three studies reported that health professionals had assumed caregiving rather than negotiated caring responsibilities with parents (Kirk, 2001; Kirk & Glendinning, 2004; Reeves et al., 2006). A common perspective reported by parents of children on LTV and with a tracheostomy was that professionals did not communicate with them how care would be provided within their home and the different roles of those involved (Reeves et al., 2006; Kirk et al., 2001; Callans et al., 2014). Kirk et al., (2001) have recommended that the initial negotiation about the care role should start in the hospital before discharge home. Discharge home from hospital was a key motivating factor for parents to learn to care for their child's medical needs, although they reflected that they had been unable to foresee the reality of caring for their child with such intensive needs at home (Kirk, 2001; Kirk & Glendinning, 2004; Reeves et al., 2006).

Mutual respect and shared decision-making is key to promoting effective communication and supportive care for children. Aspects of communication and supportive care have been explored in the literature in more depth. Mendes (2016), for example, suggests care should be shared equally between parents and nurses with control over their own areas of expertise; parents should have control over decisions regarding their family and child, and nurses over decisions regarding practice. Furthermore, parents report feeling frustrated about nurses insisting on performing their child's care in both these environments (Callans et al., 2016; Giambra et al., 2014, 2017). This is supported by Mendes (2013) who showed that although parents of children on LTV welcomed input from nurses, they felt they wanted to be in control of the important decisions about their child's care.

Eight studies reported that a major issue for parents of children on LTV and complex respiratory conditions was the way in which the clinical tasks they had to undertake to support their child's care (nursing role) dominated their parenting experience (Kirk, 2001; O'Brien & Wegner, 2002; Brett, 2004; Kirk & Glendinning, 2004; Kirk et al., 2005; Rehm & Bradley, 2005; Reeves et al., 2006; Hobson & Noyes, 2011). Typically, the extra responsibility affected their parenting role, with some parents discussing that they had multiple roles as nurses, doctors, consultant and parent (Reeves et al., 2006). Parents have reported that their role as a parent often changes because of the challenges they face of managing daily life with their child's technology dependence (O'Brien, 2001). Parental choice about taking on the caregiving for their child was constrained due to their obligation as a parent and a lack of community services (Kirk, 2001). Some parents described a sense of resentment at the way in which their nursing role could dominate their parenting experience, and health professionals' expectations of parental involvement in the care of their child can act as a barrier to the negotiation of caregiving (Kirk et al., 2001; Reeves et al., 2006). Feelings expressed by parents showed that primarily they wanted to see themselves as parents, not nurses, and they did not want their relationship with their child to be defined by nursing activities (Kirk et al., 2005).

Nevertheless, parents have to accept responsibility for their child's care and procedures and some studies reveal that this is because it ensures safe care for their child (Wilson et al., 1998; O'Brien et al., 2001; Giambri et al., 2014). Two studies reported that mothers caring for their child with a tracheostomy and on LTV felt unable to trust any carers at home with the care of their child. To establish any form of trust mothers felt the need to constantly check the care that was given by carers, and if this was inadequate, trust was lost (Wilson et al., 1998; McNamara et al., 2009). This vigilance in checking care and establishing trust meant that parents could not always get the break from caring that they sought (Kirk, 2001; Kirk & Glendinning, 2004; Reeves et al., 2006).

Social experiences of parents

The following section is divided into two sub sections and explores core elements of parents' experiences of isolation and socialization and their quality of life.

Isolation and socialisation

Eleven studies explored parents' views about isolation and socialisation and the impact this had on their lives. The literature reveals that parents across all groups of children in these studies commonly experience isolation (Cohen et al., 1998; O'Brien, 2001; Mentro & Steward, 2002; Tomment, 2003; Kirk & Glendinning 2004; Rehm &

Bradley, 2005; Hopkins et al., 2008; Mah et al., 2008; Hobson & Noyes, 2011; Woodgate et al., 2012; Callans et al., 2016). This isolation can result from a number of factors, including uncertainty about leaving the home due to technical aspects (Callans et al., 2016), and the perceived social stigma of having a child with a complex respiratory condition, tracheostomy and on LTV (Cohen et al., 1998; Tomment, 2003; Kirk & Glendinning, 2004). Parents have reported that meaningful social participation required other people to understand and accept them and their child (Mah et al., 2008; Woodgate et al., 2012). When this acceptance was not present, families limited their participation in society by choosing to stay at home or socialising with a very limited group of friends or relatives (O'Brien, 2001; Mah et al., 2008; Hobson & Noyes, 2011; Woodgate et al., 2012).

Parents may be stigmatised because of their child's appearance or disability and this is reported as leading to negative social experiences due to perceived differences between their child and other children (Woodgate et al., 2012). Parents of children with tracheostomies have reported that they feel embarrassed and indignant about being stigmatised and that they try to balance these feelings by performing clinical procedures in secrecy when out in the community (Callans et al., 2016).

Research findings reveal the challenges that some parents face in managing other people's reactions to their child's condition (Kirk & Glendinning, 2004; Rehm & Bradley, 2005; Mah et al., 2008; Woodgate et al., 2012**).** Parents in these studies described becoming accustomed to being stared at and questioned by curious people. In dealing with a lack of understanding from individuals when out in the public domain with their child with complex respiratory issues, parents reinforced the importance of having a planned exit strategy (Woodgate et al., 2012). However, some parents discussed the importance of being able to access the same places, spaces and activities accessed by able-bodied people as being important to them because it promoted inclusion for their child (Woodgate et al., 2012). Key to promoting inclusion is recognising that one size does not fit all and that not removing the barriers that parents may face because of their child's medical needs can result in isolation.

The extent of the impact of caring for their child with a tracheostomy and who is on LTV has provided evidence that marital problems stem from the additional caring responsibilities and relationship disruption (O'Brien, 2001; Montagnino & Mauricio, 2004; Hopkins et al., 2008; Mah et al., 2008). Marital discord has been linked to issues such as emotional burnout (O'Brien, 2001), not spending time together as a couple (Kirk & Glendinning, 2004), loss of privacy (Mah et al., 2008) and isolation from each other (Tommet, 2003). The parent remaining at home often comes under increased strain and is more socially isolated than the parent who goes to work (Montagnino & Mauricio, 2004).

The next section of the review will present parents' views on their quality of life.

Quality of life experiences for parents and their perceptions of their child's quality of life

The literature review reveals that both qualitative (n=5) and quantitative (n=4) research designs were adopted to explore or measure parents' views about their own and their child's quality of life. Combined, these studies give 147 parental views, with common interpretations from parents on their child's quality of life (see Table 6). From a qualitative perspective, a core finding of the review reveals that parents are committed to providing their child with a good quality of life (Wilson et al., 1998: Kirk, 2001; O'Brien, 2001; Mah et al., 2008; Woodgate et al., 2012). Parents of children on LTV report that their child's quality of life improved once they were home from hospital (Kirk, 2001) with another study noting that some parents expressed high levels of uncertainty when trying to imagine their child's future quality of life but tried to plan for this as best as they could (O'Brien, 2001). In Woodgate et al.'s (2012) study, parents discussed 'having a life' in society and the value that meaningful participation and the sense of belonging and well-being brought to them. Parents viewed their child's development and preparing for their child's future as an integral part of participation in everyday life. Interestingly, although there is quantitative evidence on parental quality of life, there are no qualitative accounts from parents about their own experiences.

Of the studies using quantitative tools to measure quality of life, none used the well-validated Pediatric Quality of Life Inventory that since 2001 has been used in over 400 published studies (Varni & Limbers, 2009). Studies focusing on families with a child with a tracheostomy that used either their own instrument, or the pediatric tracheotomy health status instrument, show a significant effect on the caregiver's quality of life because of caring for a child with a tracheostomy. Most studies report problems with sleep, relationships, social life, emotional well-being/mental health and ability to work (Cohen et al., 1998; Harnick et al., 2004; Hopkins et al., 2008; Joseph et al., 2014). Typically, parents highlighted that their child's tracheostomy places an immense burden on them and threatens their quality of life (Cohen et al., 1998; Joseph et al., 2014). Joseph et al.'s (2014) study asked seventy-one parents who were caring for a child at home who had a tracheostomy and who was on LTV, to report their quality of life on a survey incorporating the Psychological General Well-Being Index (PGWBI) scales. A PGWBI score of 73–110 is described as positive well-being, 61–71 as moderate distress, and 0–60 as severe distress (Chassany, Dimenas, Dubois, & Wu, 2014). The results indicated that parents of a child with a tracheostomy and who is on LTV at home, average scores for quality of life (64.07) showing moderate distress, indicating that the quality of life of parents of these children is lower than an average healthy person (Joseph et al., 2014).

Hopkins et al.'s (2008) quantitative study looked at caregivers (n=26) to children who had a tracheostomy rating their child's quality of life as better than their own. The quality of life of the carer was significantly associated with that of the child (p = 0.007, x2 = 33.1). Only seven caregivers rated their child's quality of life as fair to poor, and nineteen caregivers rated their child's quality of life as excellent to good, but only five caregivers rated their own quality of life as excellent. Caregivers' quality of life was linked to their reports of issues relating to sleep, relationships, social life and their ability to work (Hopkins et al., 2008).

The next section of this review will focus on how parents perceived the service that they had experienced and how they felt about the delivery of care.

Experiences of service organisation and delivery of care

The following section is divided into three subsections; ‘care packages’, ‘parents as experts’ and ‘support’.

Care packages

The majority of literature in this review has focused on parents’ experiences of care packages (Wilson et al., 1998; Noyes et al., 1999; O’Brien, 2001; Kirk & Glendinning, 2002; Mentro & Steward, 2002; Tomment, 2003; Margolan et al., 2004; Rehm & Bradley, 2005; Hopkins et al., 2008; Hobson & Noyes, 2009; McNamara et al., 2009; Miller et al., 2009; Berry et al., 2011, Callans et al., 2017). Parental views and experiences have been gained mainly through qualitative methods with one study using a mixed method approach. Co-ordinated care is key when planning and sustaining care within the home. The literature has reported a disruption in the lack of co-ordinated care for parents of a child with a tracheostomy, with a lack of knowledge from care providers about tracheostomies (Callans et al., 2017). Parents across all groups of children in the review report their central role in coordinating and arranging the care for their child (Berry et al., 2011; Kirk & Glendinning, 2002; Miller et al., 2009; McNamara et al., 2009; O’Brien, 2001; Tomment, 2003; Callans et al., 2017). This need to co-ordinate care is described as a breakdown of managing care packages, the changing characteristics of care, and the management strategies that professionals employ (Miller et al., 2009; Wilson et al., 1998; McNamara et al., 2009).

The evidence in this review shows the challenges parents’ face of sustaining a care package and achieving continuity of care. Miller et al.’s (2009) study exploring parents’ views of children with complex respiratory needs highlighted differences in managing and maintaining continuity within particular service sectors. Parents often discussed managing multiple concurrent care plans rather than one overarching plan for their child’s care. Parents acknowledged the importance of written information about their child’s care to share with providers of care to improve communication and safety (Miller et al., 2009). Giambri et al. (2017) reported that parents of children on LTV felt that achieving a mutual understanding of care planning with nurses took time to establish. However, some parents whose child had a tracheostomy explained that, although it was not their role, they had created their own care records about their child to track the care their child received (Berry et al., 2011). Typically, parents wanted to see ‘regular faces’ caring for their child because this facilitated the professionals getting to know their child (Miller et al., 2009). However, parents of a child on LTV have reported lack of co-ordination of care and minimal nursing support (Noyes et al., 1999).

Families noted the importance of being able to contact a person who was familiar with their child and the security of knowing that the professional was accessible when needed (Kirk & Glendinning, 2004). However, not all parents of children on LTV or with complex respiratory needs could identify professionals who were supportive, and some reported that they actually received no back up at all (Kirk & Glendinning, 2002; Kirk & Glendinning, 2004). Parents reported having minimal support to take care of their child both ‘day and night’ (Noyes et al., 1999; Montagnino & Maurio, 2004). Parents of children on LTV have experienced less nursing support once at home and no consistency of support from health, education and social care teams (Noyes et al., 1999).

A theme commonly reported by parents caring for their child with a complex respiratory issue and on LTV was how care in the home impacted on their family privacy. Home is usually a place where a person feels most ‘at home’, and familiar faces, furniture, sounds, smell and tastes are associated with the comforting rituals of everyday life (Mack, 1991). Parents discussed that the presence of a carer in their home led to a lack of privacy and constrained their home life (Wilson et al., 1998; Mentro & Steward, 2002; Margolan et al., 2004; Rehm & Bradley, 2005). However, some parents have talked about positive experiences, with some seeing home care support as very helpful and providing a good quality service (Hobson & Noyes, 2011; Margolan et al., 2004; Rehm & Bradley, 2005; Mendes, 2013, 2016). In conclusion, the findings from these studies are a constant reminder that service delivery remains problematic for parents in the management of care packages and this also creates personal issues in their lives. Research shows the critical role parents play in channelling and managing care packages for their child.

The following section presents the literature surrounding parents' views and the experiences of parents as experts.

Parents as experts

A theme commonly discussed by parents in this review was how their expertise in their child's care had developed over time. All the literature on parents as experts has been undertaken using qualitative methods and the studies have been conducted in the following countries; Canada (n=1), UK (n=3), USA, (n=7) and New Zealand (n=1) (see Appendix 1). The care knowledge and expertise that parents acquire over time about their child's health condition has transformed conventional parent-professional relationships and roles (Kirk, 2001; Kirk & Glendinning, 2002; Giambra et al., 2014, 2017; Callans et al., 2017). McNamara et al.'s (2009) study discusses parents adapting, learning and progressing to becoming practiced at care, developing routines and eventually knowing more about their child‘s care than health professionals.

Parents of children with complex respiratory issues talk of the need to become experts about their child's unique and often changing needs alongside developing an understanding of complicated health and social care services (Woodgate et al., 2012). Similarly, parents of a child with a tracheostomy felt that increased ownership of the caregiving role enabled them to recognise that they were becoming expert caregivers and advocates for their child (Callans et al., 2014).

A common theme from parents was that they wanted health professionals to listen to them, and recognise their expertise in their child's care, and they found this an important part of their relationship with professionals (Reeves et al., 2006; Mendes, 2013; Giambri et al., 2014, 2017). Parents have reported that professionals should acknowledge a lack of expertise in their child's clinical care as this would encourage a more trusting, open and honest relationship (Reeves et al., 2006; Callans et al., 2017). Typically, parents have described their knowledge as arising from two different sources; the knowledge of the care required including some technical knowledge, and the knowledge of their own child's likes and dislikes, what they can tolerate and therefore how they may respond to the way care is delivered on a day to day basis (Kirk, 2001; Kirk et al., 2005; Kirk & Glendinning, 2002). The literature reveals that it is important for parents to have their opinions about their child’s health valued by professionals (Kirk & Glendinning, 2002).

Some studies have found that some parents report feelings of ‘us against them’ and note that they think some professionals feel threatened by parents’ superior knowledge, which may lead to professionals not giving parents the respect they deserve (Diehl et al., 1991; Kirk & Glendinning, 2002; Mendes, 2013, 2016). Parents expressed extreme frustration when nurses discounted their expertise (Kirk & Glendinning, 2002; Reeves et al., 2006), but some parents have discussed their appreciation of nurses who asked for and used their expertise (Giambri et al., 2014).

Mothers of a child on LTV felt that they needed to develop a teaching role for professionals to protect their child and prevent serious complications to their child’s care (Wilson et al., 1998). Mah et al. (2008) describe the huge learning curve for parents to become expert parents and how stressful this learning process can be. However, once parents had achieved expertise they felt in a better position to advocate for their child’s care (Mah et al., 2008). Theories of ‘family-centred care’ have long underpinned research and policy in paediatric health care in the wider literature (Mitchell & Sloper, 2001; Law et al., 2005; DH, 2004; Kitchen, 2005; Williams, 2006). However, family-centred care studies are not evident in the paediatric tracheostomy literature.

Having discussed the concept of parents as experts this led me to review the literature surrounding the support parents receive.

Support parents receive

The need for support and the crises that some families experience due to the lack of support are common discussion points in many papers (Noyes, et al., 1999; O’Brien, 2001; Kirk, 2001; Kirk & Glendinning, 2002; Kirk & Glendinning, 2004; McNamara et al., 2009; Reeves et al., 2006; Hobson & Noyes, 2011, Tomment, 2003; Mah et al., 2008; Brett, 2004; Montagnino & Mauricio, 2004; Mendes, 2013, 2016). The evidence is mainly drawn from qualitative research that reports on 179 parent views across the cohort of children that were included in this review (see Table 5). In a small-scale study, eight fathers of children with complex needs particularly praise the role of

Children Community Nursing Team and Specialist Nurses, valuing their expertise (Hobson & Noyes, 2011). Fathers described the support received from these groups of professionals as important to them, especially when clarifying any caregiving concerns (Hobson & Noyes, 2011). The support from these groups of professionals has also been reported as valuable in another study where it promoted parental confidence and aided coping (Kirk & Glendinning, 2004). The complexity of children with respiratory health issues means that families require a good support system; however, it has been reported that there is a lack of support and few opportunities for breaks from caring for parents (Kirk, 2001; Reeves et al., 2006).

Challenges remain for professionals to provide on-going support, not just in a time of crisis, but to incorporate support as part of the everyday care that is delivered. Only one study (Brett, 2004) discussed how parents' experience support in their lives, and identified five themes; parents' feelings about support, the journey to accepting support, support as a loss, disability and the parents and the supportive relationship. Brett's (2004) study highlights parents' feelings of anxiety about asking for and accepting support as being an admission of failure. Brett found that parents' felt that professionals' needed to understand the experience of support from their perspective and understand that flexible systems of support that challenged practice were needed. To ensure that these challenges were met parents wanted professionals to listen to them, and deliver support in a helpful way. Thus, providing helpful support from professionals avoids crises such as parental breakdown (Brett, 2004). A recent study by Carter, Bray, Keating and Wilkinson (2017), which analysed the "#notanurse" but parent-driven campaign videos, reported that parents' lives are often dominated and disrupted by the many-faceted, clinical caregiving roles they have to adopt. The fact that this occurs without adequate support or resources for the parents is the fundamental driver for #notanurse_but campaign (Carter et al., 2017).

Findings from this review reveal how parents gain support from their peers and supportive networks (Mah et al., 2008; Tommet, 2003, Reeves et al., 2006). Some studies have found evidence that family, friends, and spiritual guidance have been of great support to parents (Tommet, 2003; Montagnino & Maurio, 2004; Mah et al., 2008; McNamara et al., 2009).

Having considered parents' perspectives, and noted the impact of health professionals on the lives and experiences of parents, the next section addresses the perspectives of health professionals caring for the group of children in this review.

Health professionals' experiences

This section presents health professionals' experiences that focus on their:

1. Experiences of caregiving.
   Sub theme: 'providing healthcare, education and information'.

Experiences of caregiving

The role of health professionals is crucial in providing services for the groups of children in this review (Law, McCann, & May, 2011). Therefore, it is important to understand whether they have the necessary capacity, knowledge and skills to meet the increasing demands placed on them (Abbott, Townsley, & Watson, 2005). This review shows that there are consistent messages from parents and professionals about the support and services that are provided**.** Out of the thirty-one papers selected for review only eight sought health professionals' views (Kirk, 2001; O'Brien & Wegner, 2002; Kirk & Glendinning, 2002; Kirk & Glendinning, 2004; McNamara et al., 2009; Berry et al., 2011; Ward, Evans, Ford, & Glass, 2015; Giambri et al., 2017). Four studies focused on children on LTV (O'Brien & Wegner, 2002; Kirk, 2001; Kirk & Glendinning, 2004; Giambri et al., 2017), one study focused on children with complex respiratory issues (Ward et al., 2015), and two studies focused on children with tracheostomies (McNamara et al., 2009; Berry et al., 2011).

Providing health care, education and information

Six studies have sought professionals' views on their experiences of providing care, support and education to families. All the literature on providing health care (n=4) has been undertaken using qualitative methods. There are two studies which explore the education and health information that should be provided to parents to understand their child's condition and care, and how professionals view this information-giving role about the children on their caseload. Only one study sought views from other health professionals (allied health and medical professionals) as well as nurses (Ward et al., 2015, see Table 5).

In one study, nurses discussed their role as building and maintaining parents' confidence in caring for their child, acting as an advocate on the family's behalf and providing help and support (Ward et al., 2015). Giamburi et al. (2017) discuss how nurses shared parents' desires for their child to receive the best possible care that is safe. However, on occasions conflicts about clinical care between professionals and parents did occur, creating tension between nurse and parents (Giamburi et al., 2017).

Berry et al. (2011) discuss the importance and management of health information for children with a tracheotomy. Berry's study addressed how health information and sharing contributes to parents' and professionals' perceptions of the quality of care received by children with a tracheotomy and how the exchange of health information among various providers should be improved. Professionals described disorganised tracheotomy care and health information mismanagement and that a child with a tracheotomy often has so many providers of care that it is often difficult to get one person to assume responsibility for their health information (Berry et al., 2001).

Professionals discussed their concern that parents did not have a choice about assuming responsibility for clinical procedures and the degree of choice that they could exercise when faced with professional power (Kirk, 2001). Nurses reported that they felt they had an important role to play in providing care by acting as an intermediary with other professionals on the family's behalf. These professionals also reported that enabling parents to express feelings and concerns was an important aspect of providing support. This is further supported by Ward et al.'s study (2015) that reported professionals felt it was important to deliver emotional support to parents.

However, nurses who cared for children on LTV and who had complex respiratory issues talked about accessing support and providing support as problematic, often due to the child's special needs (Kirk & Glendinning, 2002; Kirk & Glendinning, 2004). Some nurses remarked that they would like additional training in counselling skills to enable them to perform this aspect of their role more effectively (Kirk & Glendinning, 2002). Health professionals have reported the heavy burden they experienced at times because of the emotionally confronting nature of their care role for children with serious complex needs, and these professionals expressed support from colleagues as invaluable because this enhanced their care delivery and made them feel less isolated and lonely in their clinical work (Ward et al., 2015).

As advancements in clinical care have progressed medical professionals have expressed the need to continually learn and adapt their clinical practice in a rapidly changing care environment (Ward et al., 2015). Developing this clinical expertise was valued by professionals and contributed to their own knowledge and skill base. Kirk and Glendinning's (2002) study discusses teaching/education as an important element of care and that teaching in the home situation is an important role for the specialist nurse.

Professionals also reported that, at times, they felt unclear about who had the medical responsibility for the child, as poor communication across the hospital and community interface could create tensions (Kirk & Glendinning, 2004). Nurses discussed their frustration in relation to equipment and funding, in particular to obtaining supplies and care packages, with this taking considerable time and effort in securing agreement for funding and chasing up supplies (Kirk & Glendinning, 2004; O'Brien & Wegner, 2002). Nurses acknowledged that the parents were the main providers of care, nevertheless they felt they could provide some elements of 'hands on care' to give parents a break (Kirk & Glendinning, 2002). However, this was only discussed by a few nurses, who also reported concerns about the problems they experienced in obtaining respite breaks for parents (Kirk & Glendinning, 2002).

Nurses discussed that partnership between parents and themselves is an important part of the care that is provided for children on LTV (O'Brien & Wegner, 2002). Nurses also felt parents treated their child with special needs differently from their other children, in particular in relation to discipline (O'Brien & Wegner, 2002), and this study reported that nurses felt parents should be in control of their child's discipline. However, these nurses felt that as nurses they should be actively taking part in child-rearing decisions and concluded that a more systematic approach is needed to assessing child-rearing issues and the development of on-going dialogue between parents and nurses about these concerns (O’Brien & Wegner, 2002).

Summary and rationale for the current research

This narrative review established the need for a study focusing on parents’ views and experiences of having a child with a tracheostomy. The literature explored has established some important research on parental views and experiences for the groups of children in this review. However, no in-depth qualitative investigations of parents’ experiences of having a child with a tracheostomy have been reported, and longitudinal studies of parents’ views and experiences of having a child with a tracheostomy are absent from the literature. This means that there is limited evidence to guide health professionals’ understanding of parents’ experiences throughout the various stages of caring for a child with a tracheostomy. It is also important to consider that without parental involvement in their child’s tracheostomy care, this group of children would need the National Health Service (NHS) to pick up the caring responsibilities that are undertaken by parents. This led to the development of a longitudinal qualitative study to explore the subjective reality of parents’ experiences of and feelings about caring for their child with a tracheostomy.

The research question that was identified from this narrative literature review is, ‘What it is like for parents caring for their child over the first 12 months following formation of their child’s tracheostomy?’

This doctoral study focuses on an exploration of parents’ stories of having a child with a tracheostomy, at three time points during the first 12 months following formation of a tracheostomy. In the next chapter, I will outline my methodological approach and my philosophical influences and how I developed and designed my study.

CHAPTER 3: METHODOLOGY

Introduction

This chapter provides a description and rationale of the methodological approach, philosophical influences, methods and procedures used in designing and developing this study. I provide a full account of the processes for ethics approval, sampling and recruitment of participants and the methods for data collection adopted for this study. Reference will be made to issues of methodological rigour, reflexivity and the role of the researcher.

The research question for this study is: What are the stories that parents tell about their child having a tracheostomy?

Aim and objectives

The aim of this narrative inquiry study was to explore parents' stories of their child having a tracheostomy in order to generate an understanding of the complexities of their journeys.

The objectives of this study are to:

1. Explore longitudinally the experiences of parents whose child needed and had a tracheostomy
2. Highlight and synthesise parents' perspectives using a narrative inquiry approach.

Summary of the study

This longitudinal study set out to explore the stories parents shared about their experiences of their child having a tracheostomy. Narrative inquiry was adopted as the methodological approach and narrative interviews as the data collection method. Parents were interviewed at three time points; the first, before their child was discharged home with a tracheostomy, then at 3 and 12 months after the tracheostomy was formed.

Philosophical influences

In this section, I present my paradigmatic position by stating the ontological, epistemological and methodological beliefs that influenced my study. Guba (1990) proposes that the philosophical stance taken in a study reflects the researcher's understanding of what is the nature of the "knowable" (ontology), the nature of the relationship between the researcher and what they know or want to know (epistemology), and what form of inquiry they will seek to find out what they want to know (methodology). Paradigms form a connected set of beliefs which frame a research study and guide its investigation through a set of philosophical underpinnings from which specific research approaches (e.g. quantitative or qualitative methods) flow (Weaver & Olson, 2006). This study will adopt Guba's (1990) position that paradigms can guide the researcher to adopt a methodological approach to their research. Guba (1990, p11) called for researchers to "support the paradigm-methodology connection" to guide a disciplined inquiry. By presenting the paradigmatic approach selected, I aim to offer the reader both a clear indication of my beliefs and to demonstrate the coherence of the methods that I have adopted.

Various research paradigms can guide a researcher's approach and the ideas underpinning their study. The research paradigm that frames this study is constructivism. Constructivism accepts that knowledge is ever-changing and therefore positions the researcher so that they are always prepared for new directions and information to emerge (Guba & Lincoln, 1994). Crotty (1998) discusses how constructivism allows the researcher to conduct their studies in natural environments and how it challenges the belief that there is an objective truth, as it draws on the complexity of participants' opinions on the meaning of their experiences. This echoes Guba's (1990, p27) proposal that constructivism:

> *"Neither predicts nor controls the real world or transforms it but reconstructs the world at the only point at which it exists in the mind of constructors".*

Constructivism has a good fit both to the proposed study and with my own beliefs and values as a researcher and a nurse practitioner. This is because the epistemological position engages with the type of knowledge that can be sought through personal interpretation. In this study, I am interested in parents' perspectives of having a child with a tracheostomy and exploring the experiences, constructions and meanings held by individual parents. Caring for families as a nurse practitioner has led to a desire to deliberately elicit parents' subjective, personal feelings about their experiences. An outcome of understanding more about parents' experiences is the potential to improve services for these families.

By using constructivism as an underpinning philosophy, researchers can explore numerous interpretations, and many ways of gathering data are possible. Constructivists concur that there is no single valid methodology in science, but rather a diversity of useful methods. Guba (1990) states the constructivist goal is to proceed to identify the variety of constructions that exist and potentially bring them together. Since constructivists aim to construct meaning based on participants' versions of their experiences, this requires the researcher to acknowledge their own influence throughout the whole of the research study. Adopting a constructivist approach required me, as the researcher, to give thought and reflection to my influence (personal, professional and as the researcher) on the study. The basic philosophical underpinnings of this study are presented in Figure 3.1.

By adopting a constructivist approach my ontological position was relativist. According to Guba (1990, p26) a relativist position is the "key to openness" and a researcher needs to expect and demonstrate this throughout their research inquiry. By adopting a relativist stance, I believe and accept the notion of multiple realities; this means being open to how the parents had different meanings and interpretations of their experiences, and that these will differ from and may challenge my initial beliefs, understanding and meanings about their experiences. Therefore, as a researcher, I declared and followed the line of inquiry from the perspectives of the participants and embraced the diversity of these experiences. This openness will also be achieved through adopting a reflexive approach.

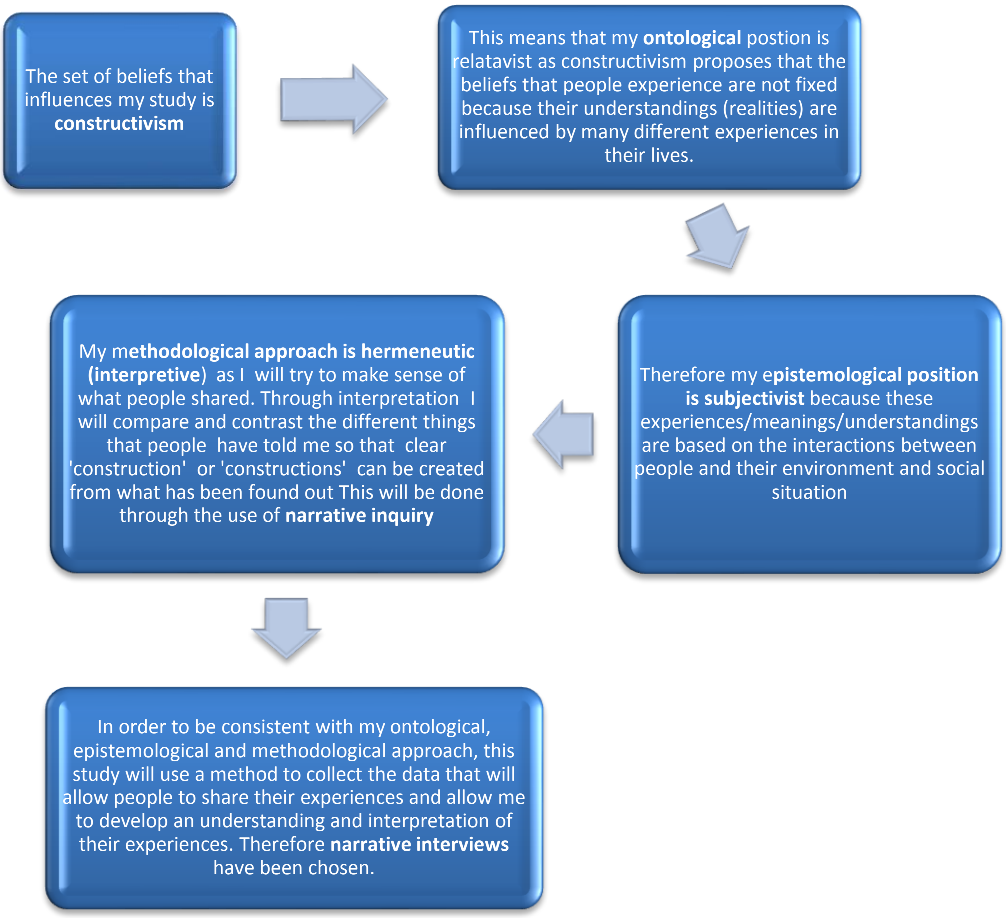


Figure 3.1: Elements that underpin the beliefs of this constructivist study developed from Guba (1990).

My epistemological position was subjectivist as I believe and acknowledge that the findings of this study were developed from the interactions between the researcher and the participants, and that the interpretations and understandings developed from these interactions. A subjectivist stance accepts and acknowledges that there is a relationship between participants and the researcher (Bunge, 1996). When interpreting the data, I tried to stay open to the meanings that participants shared whilst also acknowledging my own influences and considering how these have shaped the data. In principle, this subjective stance holds the position that participants' own feelings, beliefs and judgements about their experiences are a matter of personal opinion, that these will be shaped by their own unique circumstances, and that they will be dynamic and subject to change.

The methodological approach to this study is hermeneutic (interpretive) as my focus is on trying to make sense of what the parents have shared. By using a hermeneutic approach, I aimed to interpret the data by comparing and contrasting the stories that parents had shared with me. Parents' interpretations may be influenced by other factors such as culture, social issues, and different clinical journeys and it is important to recognize that people come from different places, backgrounds and will have different opinions (Gadamer, 1989). All of this makes the parents' interpretations, their meanings and experiences complex. I also recognize and acknowledge that my beliefs and any assumptions I hold will influence my insights and understandings and that my beliefs will have been shaped by many personal and professional sources, including what I have read within the literature and my experiences of nursing families who have a child with a tracheostomy.

Methodology

This section discusses the methodological approach and the chosen method that was adopted for this study.

Qualitative methodology

Qualitative research has many different approaches that a researcher can consider according to their own beliefs and the nature of their chosen inquiry. Lincoln (1992) summarises the general uses of qualitative research, as to grasp and understand phenomena and to emphasize immersion in and comprehension of human meaning. Lindlof and Taylor (2011) propose that qualitative inquiry strives to understand objects of interest but some qualitative researchers argue that they go beyond understanding and seek a deeper truth (Denzin & Lincoln, 1994). Considering the contribution of qualitative research, Carter and Goodacre (2012, p105) note:

> "*It is this fundamental concern with meanings, experience and trying to understand how people make sense of their worlds that make the contribution of qualitative research so potentially powerful.*"

Qualitative research provides a platform for and includes the desire to develop in-depth and interpreted understanding of experiences that draw on the perspectives of the research participants (Denzin, 1994). Most qualitative research is characterised by data collection methods which involve close contact between the researcher and participants so as to develop rich and extensive data (Welford, Murphy, & Casey, 2012). Analysing data qualitatively allows the researcher to develop and interpret the data in many ways depending on the specific approach chosen. Emerging analysis may be developed through concepts, ideas, patterns or typologies, and explanations are developed at the level of meaning rather than cause (Snape & Spencer, 2003).

Barker (2008) notes that qualitative approaches are known to enrich current understandings, particularly in under-researched areas, and thus a qualitative approach was an appropriate choice for this research study, particularly as only two previous studies (McNamara et al., 2009; Callans et al., 2016) had qualitatively explored parents' views of having a child with a tracheostomy. The absence of literature reporting parents' in-depth experiences illustrated the need for a study to adopt a qualitative approach, so as to develop a better understanding of parents' experiences of having a child with a tracheostomy.

Having determined that I wanted to use a qualitative approach, I needed to consider a methodology that would do justice to the parents' subjective experiences and would allow a creative exploration and interpretation of the data and to present a meaningful account of their experiences. Having considered different options, I chose narrative inquiry as it had a good fit with the research question and is positioned within the constructivist paradigm.

Narrative Inquiry

> *"If stories come to you, care for them and learn to give them away where they are needed."* (Lopez, 1990, p11).

Narrative research is the study of how human beings experience being in the world and narrative researchers achieve this through collecting stories and writing narratives of experience (Gudmundsdottir, 2001). Many researchers see narrative inquiry as an appropriate means of seeking and exploring meaning and experience (Riessman, 1993; Clandinin & Connelly; 2000; Moen 2006; Sparkes & Smith, 2009). Narrative approaches connect with the constructivist belief that meaning is associated with events in people's lives. Moen (2006, p4) notes that "narrative research is an on-going hermeneutic and interpretive process".

Narrative inquiry uses dialogue and storytelling to create interaction and engagement between the researcher and the participants to develop stories. Frank (2006, p422) notes that stories revise people's "sense of self" and place people in groups, that is, stories give a representation of who they are (their understanding of themselves). Schechtman (2011, p395) further discuss this as the "hermeneutics narrative view" and the strong association it has between selfhood, narrative and agency. Narrative is a means of organising an interpretation of reality as stories have the ability to resonate with us in a way that other forms of information often cannot (Riessman, 2002). People relate to other people's stories and look for similarities, differences, and resonances with their own experiences and understandings (Andrews, Squire, & Tamboukou, 2008).

A central defining characteristic of human beings is our story-creating and storytelling nature (Murray, 2002) and our stories are produced for specific audiences and are context dependent. Narrative and life go together and so the principal attraction of narrative as a method is its capacity to render life's personal and social experiences in relevant and meaningful ways (Connelly & Clandinin, 1990). I wanted an approach that would represent the individual views of the parents, and I wanted to honour their stories; I accepted that, as Clandinin and Connelly (1990) propose, stories are told across time and within their own natural environments. The approach used in this study acknowledges Riessman's (1993, p5) view that narratives:

> *"Do not mirror the world out there but rather they are constructed, creatively authored and rhetorically replete with assumptions".* (Riessman, 1993, p5).

Narrative inquiry is concerned with critical analyses of the stories we hear, read and tell on a personal level, as well as the larger societal narratives embedded in our social interactions (Webster & Mertova, 2007). Thus, I acknowledge that both parent and researcher-related factors will contribute to the development of a story or narrative. I will provide a reflexive account of myself as the practitioner-researcher and a section on power relationships between practitioner-researchers and their participants. Polkinghorne (1995, p11) notes that the value of narrative inquiry is in “noticing the differences and diversity of people’s behaviour” and I hope to explore and reveal the complexity of the parents’ experiences, and what they have learned about themselves, as well as specific incidents, moments and turning points in their journeys.

Methods

This methods section will present an account of the sampling, inclusion and exclusion criteria, the recruitment of participants, narrative interviews and the processes associated with data collection used in this study.

Sampling

Convenience sampling was used to identify the parents who were available during the study period and who met the inclusion criteria. Ultimately, a researcher wants their study sample to represent the persons in which they are interested, and convenience sampling involves constructing a sample from the population to which the researcher has access (Trochim & Donnelly, 2007). The advantages of convenience sampling include it being the easiest, least time-intensive and least expensive approach to implement. However, the potential drawbacks are that the generalisability of the results of the study is limited to the sample itself (Bornstein, Jager & Putnick, 2013). Convenience sampling was the chosen method for this study because of the relatively small number of parents with a child having a tracheostomy and the desire to gather useful data and information in an under-researched area. However, to gain as many perspectives as possible, all parents within my catchment area whose child had a new tracheostomy within the time frame set for recruitment (July 2014 to October 2014) were invited to participate in the study.

Inclusion and exclusion criteria

Potential participants for this study were parents, foster parents or main carers of a child who had recently undergone a tracheostomy procedure within the study hospital.

Inclusion and exclusion criteria for this study were carefully considered. Consideration had been given to widening the recruitment base to include other specialist children's hospitals that perform and care for children with a tracheostomy. However, whilst reaching a wider cohort of participants may have been preferable in gaining a wider view of having a child with a tracheostomy both regionally and nationally, the decision was to recruit from within the local specialist hospital. This was because firstly, I had primary access to families whose child needed a tracheostomy, and secondly due to time pressures associated with doing this PhD part-time whilst managing a considerable clinical work load. I felt that lengthy commutes to engage with families across a wider geographical area would have added considerable pressures both to the research, and myself clinically, which I needed to avoid.

However, my inclusion criteria aimed to gain diverse participant experience. The specialist hospital provides services for a large catchment area and, as a nurse practitioner with an insider's knowledge of the group of families from which I could recruit, I felt confident that I would be able to invite parents with enough diversity in terms of their stories.

Inclusion criteria

- Parents, main carers and foster carers of a child who had a new tracheostomy.
- Parents attending Alder Hey Children's Foundation Trust with their child.
- Parents of a child (aged from birth to sixteen) who has a tracheostomy.
- Parents whose child may or may not have complex health needs.

Exclusion criteria

- Parents aged under 16 years.
- Parents of children receiving palliative care.
- Parents of Children on LTV at the time of the study commencement.
- Parents with another child with a tracheostomy.
- Parents of children who lived out of my catchment area.

- Parents who were unable to sustain a conversation in English.

Parents who could not sustain a conversation in English were excluded from participation as narrative inquiry depends on the researcher's interpretation of stories. As a major focus of this work is on the language that is used to create stories, the process of translation then back translation would change the interpretation and the researcher's direct access to stories; this would create challenges for data analysis and interpretation. The nature of narrative research means the process of creating co-constructed narrative and stories strongly influences this inclusion criterion.

Recruitment of participants

The recruitment process used a staged approach. In stage 1 the child's Ear, Nose and Throat (ENT) Consultant approached potential participants and briefly informed them about the study, gave them an information leaflet outlining the study (see Appendix 4) and invited them to find out more about the study. This took place within 1 to 3 weeks of the child's tracheostomy being formed. All ENT consultants in the hospital had been informed about the study and had agreed to be involved in recruiting participants. In stage 2, if potential participants demonstrated that they were interested in the study, the researcher approached them at a suitable time for the parents and provided a more in-depth verbal explanation. I arranged a time to meet parents about the study which was separate from my clinical visits. I made it clear to the parents that the focus at this time would be about us going through the research (separate from clinical conversations) and answering any questions they had about the study. A comprehensive review of the information sheet took place through discussion with the parents. This included going through the key purpose of the study, that it involved three interviews and that they could withdraw from the study at any time. In stage 3, potential participants were then given up to 48 hours to think about the study before being approached about an initial decision to participate.

The research project focused on each parent's initial period of adjustment and adaptation following their child having a tracheostomy and therefore it was important to seek parents' experiences and perceptions during their child's period of hospitalisation. Once the parents had agreed to participate verbally the first interview was organised and the process of written consent would take place before the first interview. This interview was organised to take place 5 to 7 days after participants had agreed to be in the study. This gave them a further option to withdraw, if they so wished. I explained to the parents that even when a verbal agreement to participate in the study or a first interview date had been arranged, if their child became unwell or their family circumstances changed, I would withdraw as a researcher until the situation was stable.

Data collection

In this section, I discuss the method of data collection I chose to use for this study and the rationale for its adoption. I will discuss how I approached, prepared and managed the interviews with the parents that took place over the first year of their child having a tracheostomy.

Narrative interviews

The primary method for narrative research is the interview (Mishler, 1986) and it is the method used within this study. Interviews provide a robust and appropriate method for obtaining insights about people's experiences. The principal reason why unstructured interviews are such a good method for narrative research is that the participants are not restricted by the researcher's agenda and the researcher allows participants the opportunity to control the direction and content of the interview (Zieland, 2013). In this study, unstructured interviews with parents allow the unfolding narrative about their child needing a tracheostomy. This study has collected data with the intention of pursuing a narrative view and being particularly interested in the stories that come from the parents' experiences. According to Mishler (1986), unstructured interviews are more likely to produce stories than structured interviews, the reason being that such a format allows participants to give freer responses.

Mishler (1986) notes that the intention of interview is to generate a conversation and those narratives are co-constructed between the interviewer and interviewee. However, although narrative interviews are underpinned by the researcher relinquishing some level of control, Riessman (2008) proposes that, in some cases where the researcher wants to further explore the participants' meanings, the use of additional prompts and questions is needed, as the goal in narrative interviewing is to generate detailed accounts. While narrative interviewing allows the participants to control the interview and narrate their story in their own words, such an approach can be challenging and unfamiliar for the participants (Ziebland, 2013). Strawson (2004) argues that there is nothing natural or beneficial about perceiving and relating life stories, and he advocates that life is lived as a series of episodes with no awareness from individuals of a narrative thread to their experiences.

Taking into account the benefits and challenges of narrative interviews, this method was chosen as it offered me a unique opportunity to collaboratively explore with parents what is important to them. I chose to use face-to-face interviews with mothers and fathers or main carers. Where both the parents and carers chose to participate they were offered the option of being interviewed together or separately. The option of being interviewed together was taken carefully, as some researchers hold the assumption that joint / couple interviewing is inferior to individual interviews. One of the main assumptions of joint / couple interviews is that a couple will inevitably strive towards fronting a consistent story when interviewed about their experiences (Bjørnholt & Farstad, 2012). Linked to this assumption is the notion that one of the couple will lead the conversation and that the other person's side of the story will be overlooked, meaning that individual interviews allow each participant the chance to speak freely (Bjørnholt & Farstad, 2012). However, it can be argued that in joint interviews, partners jointly negotiate and construct their narrative (Racher, 2003). Hertz (1995) suggested that joint interviews might enable individuals to blend their perspectives and present themselves as a couple. However, Morgan (2016) states that there is little evidence to substantiate whether there is any difference in the nature of single or joint interviews. In line with my interpretive hermeneutic beliefs, which recognize that there is not one single truth but that there is a "fusion of horizons" (Gadamer, 1986, p358), I decided on offering both these approaches to the interviewees, so as to have the opportunity to gain both individual and /or couple perspectives, as they wished.

Timing and location of interviews

Since no other studies had explored parents' experiences of caring for their child with tracheostomy over time, I wanted my exploration to track their experiences over 12 months. Interviews were undertaken at three time points and arrangements for each interview made with parents (see Figure 3). The time point for each interview aimed to contribute to an overall perspective of the trajectory of having a child with a tracheostomy. The aim was to interview the parents before discharge from the hospital, then at 3 and 12 months from discharge. Ritchie and Lewis (2003) note that in longitudinal studies the number of research episodes and their timing will reflect the dynamics of the process being observed and the research objectives. I considered carefully the time points chosen for interviewing parents and these were based on my own clinical insight into my experiences of families' journeys and how they progress from hospital to home. Guidance on specific time points was not available from the literature as no other relevant studies with parents of children with a tracheostomy had embarked on similar longitudinal work. Three months seemed a good period of time following the formation of the child's tracheostomy and the child's discharge home to seek how things at home were going. The 12 month time point provided a sufficiently long period of time to explore how the parents had been adjusting to their life with a child who had a tracheostomy, as well as being a pragmatic decision in terms of the timeframe available for data collection.

Longitudinal qualitative research has the potential to be a powerful approach to understanding the complexities and turning points of individual experiences (Grossoehme & Lipstein, 2016). A major advantage of longitudinal interviewing is to be able to study the development of individuals' experiences over time. My study followed what Menard (2002) proposes as being longitudinal research; that is research where data are collected over two or more distinct time periods, the data is analysed the same across periods of time, and where the analysis involves comparison of data through time.

These interviews were arranged at a mutually agreeable time and in a quiet location that fitted with the parents' and their child's routine. The parents were contacted at each time point to clarify if they were happy to continue to be part of the research project and an appropriate date and time for the next interview arranged. In recognition of their busy and often unpredictable family lives, the parents were asked to contact me if circumstances meant that they were no longer able to commit to the agreed time. I contacted the parents a couple days before the interview to check that the date and time was still convenient.

Interview preparation

Corbin and Morse (2003) propose that interviewing skills develop with experience and that a good interviewer must be able to establish and develop rapport and trust. I developed my interviewing skills in different ways, including attending a qualitative interviewing course, and this allowed me the opportunity to meet with qualitative researchers who had experience in interviewing and to share and learn from their experiences. This fuelled my desire to improve my interviewing skills and gave me hands-on practical experience of different qualitative practices.

Even though I felt I had some interviewing experience with parents as a nurse practitioner, I did find research interviews to be different, presenting a different challenge to clinical interviewing. According to Anderson and Kirkpatrick (2016), the skills needed for good narrative interviewing include being able to establish rapport and trust early on in the interview, then being a very good listener throughout and avoiding interruptions. Therefore, it was important to be reflective about how I could improve and take my learning with me into subsequent interviews. First interviews by novice researchers are often awkward with them often feeling uncomfortable about the silences and pauses in the conversation and wanting to introduce comments and questions (Corbin & Morse, 2003). I can concur with this view, and my reflections and early reading of my transcripts helped me see my errors and in subsequent interviews there was less input from myself. I was always mindful of the advice from Goodson (2013, p36) who notes that taking a ‘vow of silence’ as an interviewer is important when interviewing because the more we question and structure an interview the less likely we are to encounter a life story.

Before each interview I prepared myself, the paperwork and the equipment required. A digital audio recorder was used to record the interviews. Before the start of the time point 1 interview with each parent, I made some brief notes on the child and family’s demographics, by asking the parents for this information. These data consisted of the child’s age, medical history and reason for having a tracheostomy. This was because I wanted to have some background (although maintaining confidentiality) information about the babies and children in my study, as I felt this information would provide context and a more holistic view that would be interesting to the reader. I prepared for subsequent (time point 2 and 3) interviews by re-reading the previous transcripts and making notes of any relevant emerging themes that I was interested in exploring further with parents. Melia (2000) suggests familiarisation with any relevant facts is important to successful interviewing. Preparation by being familiar with what participants have talked about in previous interviews also helps the researcher listen attentively and show interest in participants' stories (Wimpenny & Gass, 2000).

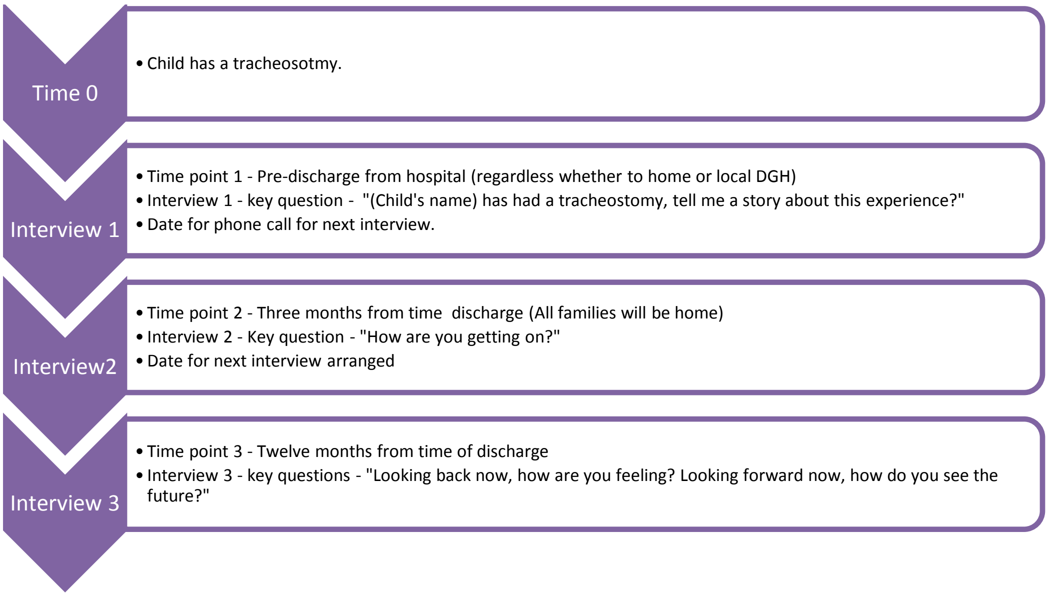
Design and conduct of the narrative interview

Narrative interviews typically start with an open-ended question about how the researcher wants the participants to tell their story and in what the researcher is interested. The direction that the interview takes is then in the hands of the participants. It is important to ask questions that will help people to tell stories about their experiences in their own way and from their own perspective. Silverman (2000) indicates that questions should tease out some theory underlying behaviour, and whilst some questions may not amount to a theory, they can provide a framework for understanding a phenomenon, which is a forerunner to a theory.

My approach to this study was not to find facts through rigid question and answer interviewing, but rather to allow the participants an opportunity to construct their stories. For this reason, parents were asked a very open-ended opening question, in order to allow them the freedom to voice their experiences of having a child with a tracheostomy. Scarneci-Domnisoru (2013) notes that the role of the question is important in narrative interviewing as it will stimulate the story. Wengraf (2004) describes the Biographic-Narrative Interpretative Method (BNIM) that guides the researcher in asking the opening question but which then hands over the control to the interviewee. Wengraf's approach seemed a good way of starting the interview and as a researcher I felt I needed to offer the parents a sense of open-ended space within which to speak. The interviews were influenced by Wengraf's (2004, p5) suggestion for an opening statement:

> *“Start wherever you like, please take your time, I’ll listen, and I won’t interrupt, you can stop at any time”.*

This opening statement was followed by specific questions at each time point. In Interview one I asked; “[Child’s name] has had a tracheostomy, tell me a story about this experience”? At interview two I asked, “How are you getting on?”, and at interview three I asked two questions, “Looking back now, how you are feeling”? and “Looking forward now, how do you see the future”?



Time 0
- Child has a tracheosotmy.

Interview 1
- Time point 1 - Pre-discharge from hospital (regardless whether to home or local DGH)
- Interview 1 - key question - "(Child's name) has had a tracheostomy, tell me a story about this experience?"
- Date for phone call for next interview.

Interview2
- Time point 2 - Three months from time discharge (All families will be home)
- Interview 2 - Key question - "How are you getting on?"
- Date for next interview arranged

Interview 3
- Time point 3 - Twelve months from time of discharge
- Interview 3 - key questions - "Looking back now, how are you feeling? Looking forward now, how do you see the future?"

Figure 3.2: Time points and key questions asked at interviews

My aim was to listen not just to the parents’ words but to also consider how they reacted non-verbally to the questions I asked. My approach was one of respectful interest, exploring and prompting when necessary but not over structuring or guiding the conversation. I aimed to allow the parents to tell their own stories in their own unique ways. I asked permission from the parents to take field notes during the interviews. The purpose here was to capture any lines of inquiry that I thought needed further investigation. Scarneci-Domnisoru (2013) proposes that taking notes during interviews makes the participants feel confident and assured of your interest as a researcher and that the interviewer can formulate clarification questions based on their notes. The overall aim was to elicit stories from the parents that followed their experiences. I anticipated that I also might need to ask the parents additional questions about their experiences on particular subjects. Therefore, I developed open-ended prompts, such as “I was interested to hear about that”, or “Tell me more about this”, to encourage more detailed storytelling (Wengraf, 2004).

If the parents became upset I asked them if they would like to take a break or stop the interview altogether (further exploration of this is provided in the ethics section). I anticipated the parents might continue to talk and share stories after the audio recorder had been switched off and there were times when this happened and the parents discussed issues or brought forth additional information. Therefore, I asked them if it was appropriate to put the audio recorder back on or if they were happy for this information to be noted down. After the interviews had drawn to an end, I spent time debriefing the parents, asking them if they were ok, happy with what had taken place and allowing them to reflect upon their interview. A debrief sheet was given to all parents (see Appendix 5 and further exploration in ethics principles section p116). After I had left the parents I made written notes to record my thoughts and reflections about the process of the interview and the stories shared (see reflection section stepping out as a researcher p131).

Modifications to interviews

After the first two interviews, I reflected on the wording of the initial opening interview question and discussed my concerns with my supervisory team. The word ‘story’ seemed to confuse parents and they seemed unaware of how to proceed and what to say. So the wording was changed to, “(Child's name) has had a tracheostomy, tell me about this experience?” as this was felt to be clearer. After using this question in the next couple of interviews, I felt that this was a better question to use and the parents seemed to talk naturally about their experiences without hesitation or confusion.

Transcription

I transcribed all the interviews as soon as possible after they had taken place to ensure that I had a very clear recollection of the interview. I made the decision to transcribe the interviews myself, as I felt that this was an important process to support my engagement with my data. Narrative analysis involves immersion in the data and I considered that this would be aided by undertaking the transcription myself (Riessman, 2008). Wellard and McKenna (2001) note that transcription forms part of the data analysis process and should be disclosed clearly in the methodology of a study. Although transcription was a lengthy process, it allowed me to get very close to the stories and also to develop a very clear sense of the stories and how they were told.

In considering transcription conventions, I decided to include utterances, laughs, emotional responses and silences in the transcripts as these helped to provide a platform for the parents' stories to be heard. Including these elements was supported by the fact that I had written in my field notes any actions and emotional responses that I observed during the interview**.** MacLean, Meyer, & Estable (2004) have explored the extent to which nonverbal cues (e.g., silences and body language) and emotional aspects (e.g., crying, coughs, and sighs) should be incorporated into transcribed text. Incorporating verbatim transcription and nonverbal actions of the participants' (observed by the researcher) has been discussed as essential to the reliability, validity, and accuracy of qualitative data collection (Seale & Silverman, 1997; Wengraf, 2001; MacLean et al., 2004). Transcribing all of the interviews was difficult and time-consuming, however, on reflection it was a learning experience that I am glad was undertaken. It allowed me some early thoughts into the meanings, beliefs, thoughts, experiences, and feelings of the parents. I numerically ordered each line of the transcripts using single line spacing to support the ease of subsequent management and analysis (see Appendix 6). This was time-consuming and involved continual stopping, starting and checking to ensure each sentence was accurately represented in written form. After listening a few times, it was possible to hear with greater ease the natural flow of what had been said.

All transcripts were anonymised. This anonymisation included removing any specific identifiable clinical information, the names of participants and their family, hospitals and any professionals that were mentioned by the parents. I created pseudonyms for parents/siblings as needed. I asked parents if they would like to choose the pseudonyms, and all but one parent left the choice to me. I ensured that the pseudonyms did not start with the same letter of the alphabet or have any resemblance to their original or cultural names . I decided to use pseudonyms rather than numbers because I felt it created a stronger sense of the story being told by real people.

Ethics

This section focuses on what has guided my thinking to develop a study that is rigorous and ethical. I present sections on the approval process for the study and the ethical principles that underpinned the study. I present a section on informed consent showing how the parents were given information and the time to decide on an informed decision about participating. I then present a section on participants' well-being before I explore issues related to being a researcher-practitioner.

Ethics approval

Prior to commencing my study, ethics approval was obtained in April 2013 from the Research and Development Committee at Alder Hey Children's NHS Foundation Trust (see Appendix 7). It then proceeded to the National Research Ethics Service (NRES 13/NW/0349, see Appendix 8) who approved my study in July 2013. I attended the NRES ethics committee meeting with one of my academic supervisors. A discussion took place with the committee around my clinical role and research role and I advised the committee of the two key ways I intended to manage possible conflicts between the two roles. Firstly, asking ENT consultants to make the first approach to families about the study aimed to reduce pressure on the parents to participate. Secondly, I explained how I planned to reflect on both my roles throughout the research study. The committee also advised me to produce a debrief sheet and they made recommendations on changes to the participant information sheet and consent form. These changes included:

- Rewording the first sentence about the purpose of the study to make it clear as to whether it is the first 12 months since having the tracheostomy or the first 12 months of the child's life.
- Revising the third sentence to make it clear that interviews would take place at 3 and 12 months following discharge home.

- Clarify how long interviews may take and add that digital audio recordings will be taken. State audio recordings will be destroyed and when this would happen
- Provided more information about the potential for participants who may become distressed. Include services that they can contact
- Information about what to do if they want to make a complaint and contact details for someone independent of the study.
- Seek consent to be contacted for follow up interviews and record preferred contact details.
- Seek consent to be sent results of the study.

The University of Central Lancashire, Building, Sport, Health (BuSH 151, see Appendix 9) Ethics Committee also approved my study in July 2013 on receipt of approval from NRES.

Ethical principles

A classical definition of ethics stated by Beauchamp and Childress (1989, p4) is to "to do good and avoid harm". The ethical principles that underpin my study are influenced by Beauchamp and Childress's (2013) notions of autonomy, non-maleficence, beneficence and justice. These four principles are not specific for biomedical ethics as they form the core part of a universal common morality. This study conforms to the ethical guidelines of the Royal College of Nursing (2009), Nursing Midwifery Council (2015) and Research Governance Framework for Health and Social Care (Department of Health, 2015).

In the following sections, I present each of these four concepts and demonstrate how I practically applied these in relation to various factors such as informed consent, concern for participants' well-being and confidentiality.

Autonomy

Beauchamp and Childress (2013, p4) describe autonomy as the "personal rule of the self" that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding. In a medical context, respect for a patient’s autonomy is considered a fundamental ethical principle, and this belief is the central premise of the concept of informed consent (Das & Sil, 2017). In the next section, I present the informed consent process for my study and how I tried to ensure autonomy.

Informed consent

At the first interview (time-point 1), written consent was obtained using a consent form devised by myself with the support of my supervisory team and developed from the standard NRES research consent form (see Appendix 10). Before consent for the first interview was obtained a comprehensive and sensitive discussion between myself and the parents took place about the study that included a review of the information sheet. This allowed the parents the opportunity to ask questions and gain sufficient information to make an informed decision. I was very aware that the parents were in a stressful situation with their child just undergoing surgery so I took this carefully into account. When I was sure that the parents felt confident about and understood the purpose of the research, the issues of confidentiality and anonymity and the voluntary nature of participation, I asked them if they would like to take part. If they wanted to they were asked to sign the consent form. At each subsequent interview, continuing research involvement was discussed with the parents and consent was reaffirmed verbally. I reassured all parents that withdrawal of consent would not affect their child’s care.

Beneficence and non-maleficence

Beneficence and non-maleficence are closely related (Freeman, 2011). The principle of beneficence refers to the moral obligation to act for the benefit of others or doing good, therefore improving the situation for others. According to Kinsinger (2010) professionals have a foundational moral imperative to do right. The principle of non-maleficence is the obligation not to harm others and myself. Munson (2004) states that if you have knowingly subjected a participant to harm or unnecessary risk you have violated this principle. In this next section, I present how I took steps to protect the parents and myself by acting in everyone’s best interests, and how I addressed my dual role as a practitioner-researcher.

Participants' well-being

The nature of qualitative interviewing may bring to the surface difficulties that cannot always be anticipated. Therefore, it was important that I explored ways that would support parents if such an event happened. After each interview, a debrief information sheet was given to the parent(s) and I ensured that there was time available for debriefing. The debrief information sheet included details of support agencies (e.g. Face 2 Face support which is a service at the study site which offers emotional support to any parent/carer of a child with disability or complex needs) and the researcher's contact details. The Psychological Services department at the study site had agreed to offer support if participants required this service. If parents became distressed during interviews I asked if they would like to pause, take a break, stop or were happy to continue. As Dyregrov (2004) argues, participants in some studies are vulnerable and special consideration and sensitivity is required on the part of the researcher. Support to parents was offered in a sensitive manner and parents were in control of what stories they shared (see reflection on emotional experiences).

Paramount to the participant opening up and sharing their experiences is trust and understanding of their situation. A previous professional relationship between researcher and participants can enhance rapport and empathy (McConnell-Henry et al., 2010), although I needed to be careful that I did not use this existing relationship inappropriately. By reinforcing confidentiality and anonymity, my aim was to allow parents to open up, if they so wished. Providing feedback to parents and thanking them for their input is important for successful disengagement from the interview. My aim was to ensure that any threats to the parents' emotional well-being was minimised.

My intention was to make the purpose of the study clear to the parents through both discussion and the information leaflet. However, I was conscious that the parents might not be prepared for or aware of the stories that they may share. Ritchie and Lewis (2003) explain that interviews can have 'seductive' qualities and that participants can share information in the moment and later regret what they have said. To try and plan against any 'regretted stories', I assured the parents that if they did not wish their interview to be included in the study their recordings would be deleted and their transcripts destroyed. I also explained that this decision about withdrawal of interviews from the study could happen up to 4 weeks after the interview had taken place.

Confidentiality

Throughout the process of the study the parents were assured that their personal information would remain confidential and be anonymised with pseudonyms. This was addressed through the written participant information leaflet and discussed verbally with parents. After transcription, the audio-recordings were erased. Prior to transcription the raw data was stored securely on a password protected computer and was only accessible by myself. All anonymised data could be shared with the supervisory team and this had been approved by the NRES ethics committee. The anonymised transcripts were kept separate from the recruitment information which I kept locked in a filing cabinet in line with hospital and ethics policy. Parents were informed that extracts and sequences from their interview could be used in reports from the study and that there was potential for publication of these in journals, conference proceedings and poster presentations. I was prepared for the possibility that participants might disclose concerns, safeguarding issues or aspects of how they managed their child's care in a way that might cause harm. I decided that if such instances were divulged I would first discuss these issues with the parent and then report in line with hospital safeguarding practices, ensuring that any issues were reported to the appropriate teams with the knowledge of the parent. No safeguarding issues or aspects of care that might cause harm arose during the interviews and so no action had to be taken.

Safety and other researcher-related issues

To ensure my safety as a researcher I adhered to the lone worker policies of my hospital and the university. I visited the parents in their own homes to undertake interviews. Therefore, upon arriving and leaving each interview, a mobile phone call was made to a member of the supervisory team or nominated individual providing a detailed location and expected time of leaving. I undertook risk assessments (e.g. this related to weather, time of day or night, destination) in relation to traveling to and from each interview.

Practitioner-researcher related issues

It is acknowledged that researching your own caseload can provide both opportunities and challenges (Knafl, Bevis, & Kirchoff, 1987). I acknowledge that researching my clinical caseload has had an influence on this study because of my prior and continuing involvement as the nurse practitioner in some of the clinical care of the children in this study. In order to address this, I used reflection to try and understand what these influences were and the impact they might be having on the study. I wrote reflective accounts of both of my roles and reflected on the interviews and other aspects of the study. In my reflexive accounts I acknowledge my own assumptions and biases and keep them in perspective. Key to keeping my assumptions under control was a willingness to listen, reflect and gain support from my supervisory team. Gatfield (2005) discusses that support from supervisors when doing a PhD is a key aspect of the relationship.

My role as the researcher was clarified at the beginning of each interview and it was explicitly stated that in this context I was acting as a researcher. As the researcher, I was aware that role confusion may arise and I was on guard to reduce this influence (Asselin, 2003, see reflection section on interviews). If any clinical issues arose, I dealt with them either before or after the interviews, and I let the parents decide which of those times was convenient to them. Most of the issues were about ordering consumables, or minor infections, and one father had found a suction catheter which was smaller in length.

Justice

The principle of justice refers to equal share and fairness. One of the crucial and distinctive features of this principle is avoiding exploitation, coercion and abuse of participants (Orb, Eisenhauer & Wynaden, 2001). In the next section I present how I sought to protect the parents and to be open with them about this study.

Recruitment process

In order to have a just and fair recruitment process, whoever was eligible to participate was approached. There were no exclusion criteria for families who lived a long way from the hospital and no family was excluded on the basis that gatekeepers considered that they were ‘difficult’ or ‘aggressive’ or because of ‘social issues’. Also careful consideration was given to parents feeling obliged to participate even if they did not want to take part in the study. A robust and fair recruitment process (see p.99 - this chapter) was put in place to avoid this, and parents were told many times that they were free to leave the study at any time (one parent did) without any impact on their child's clinical care. It was important that parents did not feel any coercion to take part in this study and that they were happy to share their experiences freely with me.

Data Analysis

In this section, I provide an overview of the different analytical approaches I considered, before providing a detailed account of the approaches I used to explore the data and how I analysed the parents' stories. I aim to make clear the choices I made and the approaches I used to engage in and analyse the data.

Possible methods for analysing the interviews

To identify narratives and/or stories different analytical methods can be used to analyse data; some are more structured and sequenced than others. Sociolinguist William Labov's (1972) structural categories are one method by which to organise the analysis of narratives. Labov argues that every well-formed story has a common set of six elements: an abstract, orientation, complicating action, evaluation, resolution and coda. With these structures, a teller constructs a story from primary experience and interprets the significance of events in clauses and evaluations (Riessman, 1987). I rejected this approach as I wanted to try and find an analytical perspective that was less structured and which would do justice to parents' extended accounts of their experiences. I also believed that my study has a focus on what the parents' stories say about themselves (their 'self') and what they bring to the meaning of their individual experiences. I felt that this would be lost using Labov's approach.

Having rejected Labov, I started to explore the work of Frank (2010), who proposes a socio-narratology approach which considers issues such as the purpose of stories, what impels people to tell stories and what type of stories are told. Frank (2010) discusses that in partnership with the theoretical approach of socio-narratology, dialogical narrative analysis (DNA) allows the researcher a way of "letting their stories breathe" (Frank, 2010). The focus of this method is on what is voiced in a story, the subject of the story, and the effects of telling a story (Frank, 2010). However, there are no specific analytical steps to follow or implement. What DNA seeks is “movement of thought during analysis” (Frank, 2010 p72). The challenge for researchers is to think critically and consider the questions that Frank suggests as prompts, if they think they are appropriate to their data.

Arguably there is a structured position to Frank’s approach which is similar to Labov’s work. Frank (2010, p27) suggests that the “capacities of stories” can provide the researcher with a list of concerns and issues to consider when managing their data, and his examples include trouble, character, point of view, suspense and out of control. However, initially my focus was to implement a method that was less structured so I rejected this approach and made a decision to explore the work of Riessman (1993, 2008).

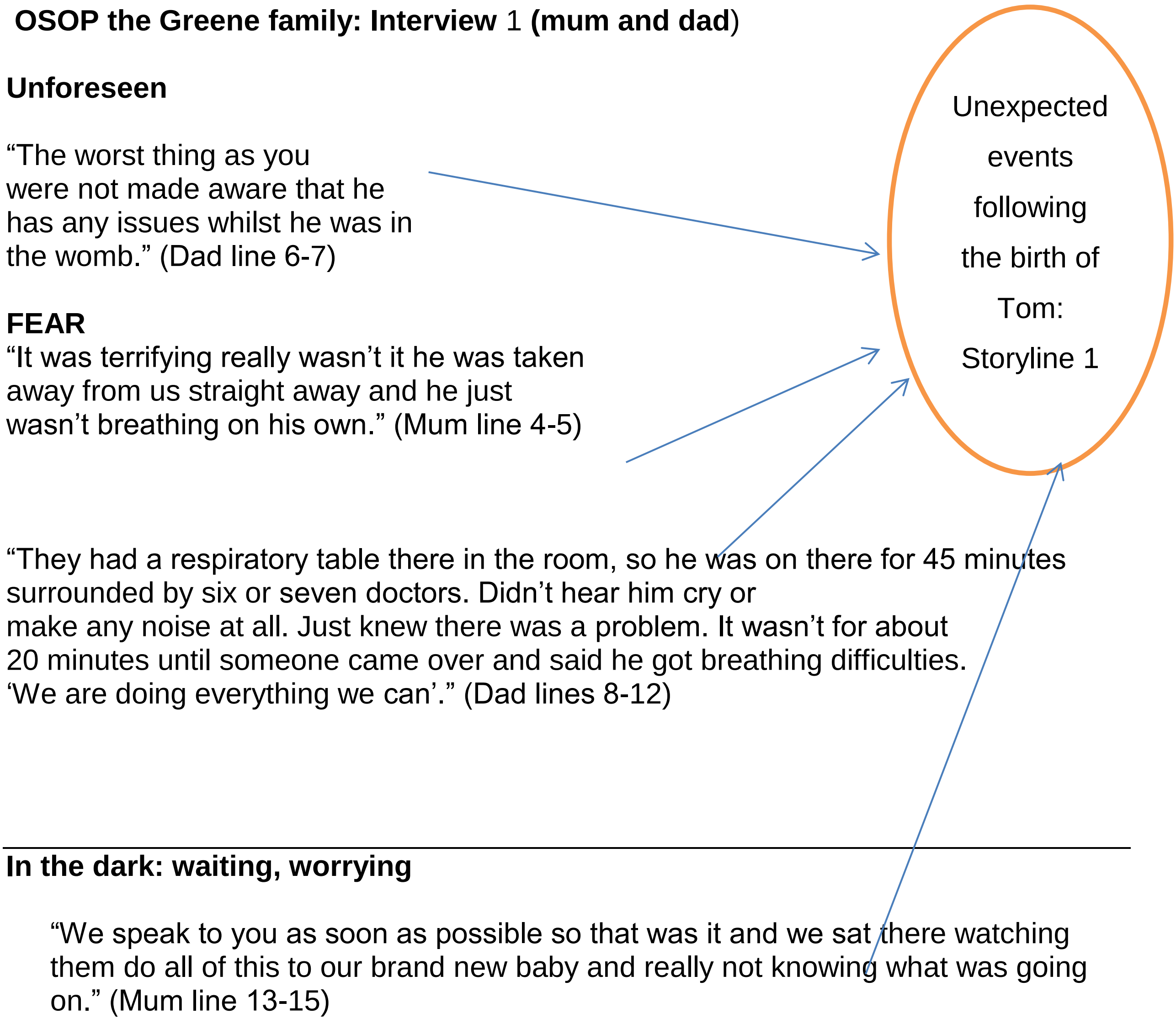
Riessman (2008) offers a typology of the four main types of analysis; thematic, structural, dialogic and visual. She discusses that boundaries between these four types can sometimes become confusing. Thematic narrative analysis focuses on the content of ‘what is said’ and can differ in the extent to which structural aspects, language of the narratives and content are attended to (Riessman, 2008, p53). Structural analysis focuses on “how a story is told looking at sequencing, certain words and metaphors” (Riessman, 2008, p77) and dialogic analysis approaches the data by asking “who, when and why?” (Riessman, 2008, p105). Riessman (2008) discusses this approach as being more about analysing social objects, society and culture and being less focused on people.

In developing the process of analysis of the stories in my study and from my reading, I had initially been influenced by the writings of Riessman (2008, 1993) and looked at applying thematic narrative analysis which focuses on “what is said” to analyse the individual stories that participants tell. This approach to analysis is methodical, focused and detailed while still retaining a sense of the “whole story” (Riessman, 2008). Most importantly, thematic narrative analysis seeks to preserve the wealth of detail in long sequences (Riessman, 2008). In my study, I hoped that thematic narrative analysis would help preserve a sense of the “whole story”, as I believed each story told by parents about having a child with a tracheostomy would be unique. I believed that this approach would allow me to remain faithful to the parents' thoughts and ideas without getting lost in codes, themes or overanalysing their views and experiences. I anticipated that this method would allow me to develop each individual parent's story as a "whole".

Analysing the interviews

Having made a decision to use thematic narrative analysis (Riessman, 2008), I applied this method to my data. I had an abundance of data and also used a technique called the one sheet of paper (OSOP) advocated by Ziebland and McPherson, 2006 (see reflection on data analysis p136). I anticipated that as a secondary method this would facilitate the bringing together of the data. The use of the OSOP in conjunction with thematic analysis assisted with organising and visualizing the data and permitted me to develop an ordered explanation of what was going on in the data. Using an OSOP for each family (see Figure 3.1) along with thematic analysis (see Table 7 for example of preliminary thematic analysis) allowed me to create a synopsis of the key ideas, storylines and sub themes.

Figure 3.3: An example of a storyline plotted in an OSOP.



OSOP the Greene family: Interview 1 **(mum and dad**)

Unforeseen

“The worst thing as you were not made aware that he has any issues whilst he was in the womb.” (Dad line 6-7)

FEAR
“It was terrifying really wasn’t it he was taken away from us straight away and he just wasn’t breathing on his own.” (Mum line 4-5)

“They had a respiratory table there in the room, so he was on there for 45 minutes surrounded by six or seven doctors. Didn’t hear him cry or make any noise at all. Just knew there was a problem. It wasn’t for about 20 minutes until someone came over and said he got breathing difficulties. ‘We are doing everything we can’.” (Dad lines 8-12)

Unexpected events following the birth of Tom: Storyline 1

In the dark: waiting, worrying

“We speak to you as soon as possible so that was it and we sat there watching them do all of this to our brand new baby and really not knowing what was going on.” (Mum line 13-15)

Table 6: Example of an OSOP storyline

The Greene family	Storylines	Sub-themes
Time point one interview	Storyline 1: Unexpected events following the birth of Tom.	Fear, unforeseen, in the dark.
The Greene family	Storyline 2: Travelling to get specialist care required for Tom.	On the move, assessment by different health professionals no time to do the natural things.

Although both these methods were helpful in the fact that they brought a lot of data together, it became apparent that Riessman's thematic narrative analysis approach and the OSOP methods were not facilitating the deeper analysis and understanding of my data that I had anticipated. I ended up with lots of storylines (the Greene family had 10) and was not sure what I should do with them.

On reflection with my supervisory team a decision was made to revisit Frank's (2010) socio-narratology (DNA) as it was thought that perhaps a more structured approach would be of some advantage. I reflected on this change of view and made notes of this (see reflection on data analysis). I found that applying the questions of storytelling practice that Frank asks the researcher to consider allowed me to gain a deeper understanding and a different view and stronger insight of the main experiences that the parents had shared with me. Frank's (2010, p75) suggestion draws attention to the particular work that stories have the "capacity to do", so I worked through these questions:

1. What makes a story narratable?
2. Who is holding their own?
3. Who is finding it difficult to hold their own?
4. What is the force of fear in the story?
5. What are the forces of desire?
6. What's at stake and for whom?
7. How is the stake reduced?

8. How do people remember who they are?

In the end these questions made me think more critically; they did what Frank's approach proposes, and allowed me a method of movement of thought from within my data. Frank (2010, p73) states that an analytic or interpretive thought that is moving allows and recognises change in the thought being interpreted. This aspect of DNA was particular powerful for me as I became more immersed in the data the more I thought about the questions. This in turn allowed for a deeper analysis and development of 'my' stories (not as whole stories as was my initial intention) allowing them to breathe and grow (see Appendix 11).

Quality of the study

Many researchers, particularly those from a narrative tradition, have argued that there can be no formal rules for validity as values of quality, like all social knowledge, are ever-changing (Denzin, 2000; Lincoln & Guba, 1985; Riessman, 2008). In keeping with my view of constructivism with its relativist ontology and subjectivist epistemology, I draw on the notion of goodness (Arminio & Hultgren, 2002) in considering the quality of this study. What is known about the goodness of research comes from engagement in the understanding and thinking by the researcher about their study. Therefore, the qualitative researcher who evidences goodness is likely to be more informative and forthcoming about locating situatedness, trustworthiness and authenticity throughout their research study (Arminio & Hultgren, 2002).

Goodness is not a separate concept but it is an integral and embedded component of my research study. According to Morse, Barrett, Mayan, Olson and Spiers (2002), qualitative research does not progress from one phase to another but requires the researcher to be continually moving in and out of their project; consequently goodness becomes an embracing concept of qualitative inquiry. Goodness requires that the following elements are embedded and central to the research process; the epistemological and theoretical foundations need to be linked to the selected methodology, the method of data collection and its analysis should be clear, and there should be evidence of reflection, meaning making, and implications for practice (Arminio & Hultgren, 2002). Goodness offers the researcher a means of locating situatedness, trustworthiness and authenticity (Denzin & Lincoln, 1998; Arminio & Hultgren, 2002).

Engaging with the elements of goodness

I believe I have demonstrated throughout my thesis the elements of goodness. I have set out my situatedness by stating my philosophical position and discussed my constructivist view. I have made clear that the parents are the experts about their own individual experiences; this is also in keeping with my subjectivist epistemological position. I have chosen narrative inquiry which firmly sits within a qualitative methodology approach. I have been explicit about my choice of narrative interviews as my data collection method and I have demonstrated how I managed the interviews. My reflective accounts attempt to provide the reader with an honest and transparent account of my relationship with the parents as well as a systematic account of my personal journey as a practitioner-researcher. I have expressed my trustworthiness and authenticity through the ethical principles of autonomy, beneficence, non-maleficence and justice and related these to how I approached consent, the participants' well-being, confidentiality and practitioner-researcher issues. In the next section I will explore the issue of the power relations between practitioner-researcher and participants.

Power relationships between practitioner-researcher and participants

In this section I will consider the potential tension and unequal power relationship that can occur between a practitioner-researcher and participants. I will discuss how my role as a practitioner had the potential to influence researcher-participant interactions.

At its broadest, practitioner-research can be defined as research that is undertaken by a person who has knowledge, expertise and insight into the people and the settings being researched (Jack, 2008; Drake & Heath, 2011). Practitioner- researchers need to pay attention to the ways in which the effects of power and knowledge connect and shape their understanding of whose and what knowledge is the most important. When considering the ability of the practitioner-researcher to draw upon alternative meanings from situations in which they are engaged, attention must also be given to the effects of power. Although qualitative research may aim to minimise power imbalances between researcher and participants, power relations may still exist during different stages of qualitative research, with the researcher possibly perceived as the “owner expert” of knowledge (Kendall & Halliday, 2014).

As a nurse practitioner, I had either a previous or existing clinical relationship with the children and their parents who might participate in my study, and I was aware that adopting a role as a practitioner-researcher would give me unique access to their stories in a way I would not ordinarily have. As a nurse practitioner in a specialist children’s Trust, I am not always privy to the ongoing lives, challenges or achievements of families once they are discharged home. It is only if their child is readmitted to hospital, attends clinic or if their parents or community teams require specialist advice that I come into contact with them again. When I was beginning to develop my research study, I thought through the complex challenges related to my being a practitioner-researcher as I appreciated I would have an ‘insider perspective’. This careful thinking through was important as there were times during the study when parents shared a wealth of information about their lives with me as a researcher that they had not shared with me as a nurse (see p135).

Being a practitioner-researcher is a nuanced position replete with both challenges and positive issues. Costley and Gibbs (2006) propose that as an insider you are in a unique position to study a particular issue in depth and you additionally have special knowledge about the issue and easy access to people; these factors can enhance the study. McCormack (2009) argues that a practitioner–researcher needs to focus on a disciplined critique of both practice and themselves (in particular who they are, and their identity), so that they are able to generate new understandings about practice and consider social, cultural, discursive and relational elements that may permit or get in the way of effectiveness and experience.

Practitioner-researchers have often been criticised for a lack of critical distance from their work. Therefore, one of the greatest challenges for practitioner-researchers is to be open about the knowledge they have gained from their own practice and what they have learnt as a result of their research study. My study has been framed within a constructivism paradigm. I was aware that my values and beliefs, the environments I have worked in and learned within will have shaped my opinions. I knew that I needed to be aware of my own biases and assumptions and, as Appleby (2013) notes, how these could always influence the interpretation of data and my construction of new knowledge.

McCormack (2009, p34) discusses the danger that lies in practitioner research if it is a “solitary and individualistic activity”, and to prevent this happening he proposes three modes of engagement that practitioners could consider. Mode 1 is “practitioner led” but managed within a framework of organisational support. Mode 2 is “practitioner collaborative” where the practitioner is engaged in the research, it is their own work and development but there is a formal collaborative or supervisory relationship that provides a supportive infrastructure. Mode 3 is “practitioner focused”, where the practitioner carries out the study but an academic researcher from a higher educational institution takes the lead. Although I had not read McCormack’s work at the outset of my research it is clear my study falls within the “practitioner collaborative” mode, given that I undertook this research with the support of a supervisory team. Thus, I was able to avoid the dangers that McCormack warns against of being solitary and individualistic.

Arber (2006) states that the use of reflexivity in qualitative inquiry facilitates the process of scrutinising the impact of the nurse-researcher on all aspects of the study process including the collected data. Reflexivity plays a key role in helping the practitioner-researcher to examine and address any influences, such as the impact their researcher role may have clinically, and subject this to critical scrutiny. Jack (2008) proposes that it is the researcher’s responsibility to be reflexive, and McCormack (2009) discusses that a researcher who adopts reflexivity must be aware of themselves and how they relate with others in the research context, explaining that this can result in a critical, rigorous and ethically sound research study. I have been reflexive throughout my research and have paid particular attention to how my prior knowledge and experience may have influenced data collection, data analysis and the construction of the discussion of my findings. Initially when attempting data analysis I realised my thinking was shaped by clinical priorities/themes and I reflected on this with my supervisory team. The outcome was a deliberate attempt to develop my researcher skills by digging deeper, being more reflexive and putting aside my ‘clinical thinking’.

Undertaking practitioner-research can create tensions between participants and the researcher and it is impossible to reduce all inequalities of power (Schratz & Walker, 1995). As a practitioner-researcher I had clinical power and status in relation to my role as a nurse practitioner providing clinical care for the child. My role as a researcher may also have been seen to be powerful particularly when recruitment was occurring within the clinical setting (Peel, Parry, Douglas, & Lawton, 2006), and practitioner-researchers who research their own caseload have to be extremely conscientious to ensure that people are not pressured to participate. As a result of wanting to reduce any perceived pressure I was not involved in the initial approach to parents about the study. Initial contact about the study was done by the ENT consultant (see p78 for recruitment process). Another way of trying to reduce any possible tensions and power inequalities was my commitment to build trust and rapport with parents, and as other researchers have found, this was a crucial component every time engagement took place with participants (Ceglowski, 2000; Goodwin, Pope, Mort, & Smith, 2003). This belief has also shaped my commitment to build trust and rapport with the parents in my study.

One of the areas of tension lay in my responsibility as a practitioner-researcher to effectively manage situations if and when parents revealed things that gave rise to me feeling some level of concern about the safety of the child or their own well-being. There were some situations where I became somewhat concerned (e.g. when a mother had been distressed during the interview, or when clinical issues arose). I did in these situations take steps to establish if the parents needed additional support and considered what actions, if any, I should take both as a researcher and a practitioner to intervene on their behalf. In one particular situation that focused on the difficulties a mother was having with her daughter’s care package, I checked with the mother after the interview if she was ok, and she assured me that she was fine. Together we agreed for me to contact her in a week’s time to check the situation. At our next contact the mother indicated that the problem had resolved and as a result, I felt confident that I did not need to take any further action. Nevertheless, this incident exposed the gaps in psychological support for families, as in the absence of the research study this mother's distress would not necessarily have come to light. The implications of this and gaps in routine psychological support are considered in the final section of the thesis.

A core issue that a practitioner-researcher has to consider and reflect upon is how to deal with any poor or ineffective practice that is uncovered during the course of the research. I was aware that my responsibility as a practitioner would always need to supersede my interests as a researcher and that I would, as necessary, have to step out of my role as practitioner-researcher and adopt a primarily practitioner role and address any clinical oversights in care. Fortunately, no issues arose about safeguarding or poor practice whilst undertaking my field work. In conclusion, the practitioner-researcher needs a level of preparedness for undertaking their research study. A reflexive approach will enable an understanding of how the two roles may impact on those people being researched and the study in the broader sense. It also means that the practitioner-researcher has to acknowledge the power-relationship with their participants, and how this is managed.

Reflections on stepping out as a researcher

In this next section, I provide a reflexive account of my journey as a practitioner-researcher within this study. My reflections have mostly been detailed accounts of how the parents had been within the interview (e.g. emotional, happy), how we had debriefed after the interviews, and how I felt about the interview. My research journal and field notes have been what Nadin and Cassell (2006) describe as a forum for me to record concerns and experiences that might have otherwise been lost or simply not considered. I made some choices within my research study that show that I have an active influence on my study and the research process. As Navarro (2005, p430) notes we need to reflect "on how we construe our identities as producers of research from a methods perspective". Being reflexive about my beliefs and values and how they impacted on my thinking is an important element to reveal how I have grown as a researcher; I have italicised my learning and thought processes to show the reader my learning journey.

Reflections on my interviews

I interviewed nine families and undertook twenty-three interviews. When I was planning my interviews, I wanted to be able to let parents talk about their experiences without restrictions or imposing structure. My plan at time point one interviews was to ask one question and 'sit back' and let parents talk. At time points two and three interviews I planned to ask a question and then let parents talk, asking probing questions at the end if deemed necessary about their experiences from time point one. I realised this was *'not going to be easy for myself as a novice researcher*'; I was concerned that I would not be able to manage the '*freedom*' for the participants that this type of interviewing would bring. With support from my supervisory team and my reading I was able to understand that my role was to be impartial, to collect information, and to listen to parents and interpret the data. I was also excited about interviewing and looking forward to undertaking fieldwork. Interviewing the parents has been a wonderful experience for me. Like Lamb (2013) my interviews were enjoyable and stimulating and were a source of motivation that gave momentum to my research study. Reflecting back, I note that I have developed my interviewing skills and have come to feel much more confident. In my field notes on my last interview I wrote about the *'sadness'* I felt that all my interviews had now been completed.

My reflective notes also document my realisation that I was a performer. When I was conducting my interviews, I developed a different approach to presenting myself to parents to my usual clinical role. Zinkin (2008) notes that the self comes into existence and will be formed, created and made. I changed my presentation of *'self'* by choosing to wear jeans and shirt as a researcher rather than my clinical uniform. I felt that the symbolic role a uniform has as a nurse could have impacted on the way the parents saw my role as a researcher. This also helped me, in an odd sort of way, to distinguish between the two roles. Even if I was seeing parents after work near the hospital I changed my clothing.

From being an experienced nurse to being a novice researcher

I believe myself to be experienced in clinically caring for children and their families with a tracheostomy. In my study, I was not there as a nurse but as a researcher, and nurses who become researchers have evaluated and reflected on starting out as a novice researcher (Taylor, 2003: Moss, 2005; Clancy, 2007; Wilson, 2008). I made it clear to parents that this was my role but I did recognise that I did not come to this study value-free. I had a vast amount of clinical expertise in tracheostomy training and developing the competency required to care for a child with a tracheostomy. I have experienced many parents' journeys before and after their child needed a tracheostomy.

Reflecting on my early experiences of the interviews I soon realised that in the researcher role I was a novice and that a '*shift in my expert-clinician position'* had occurred. Parents, arguably, were now the experts and I felt honoured that I had the opportunity to explore their experiences over the first year. I came to acknowledge that despite my knowledge and expertise as a clinician I had not really fully understood what parents go through.

In the following sections I reflect on some of the aspects of interviewing that were challenging to me as a researcher.

Silences

In my first interview with the Greene family my field-notes record that I found the silences *'hard, even seconds seemed like hours'*. I reflected on how I wanted and at times did ask another question to fill in the *'gaps'*. However, as the interviews progressed and as I started to read the transcripts, I became aware of the importance of silence and in my field notes I wrote *'silences are powerful'*. Sharpley, Munro, and Elly (2005) propose that attempts to fill silences with questions probably do not contribute towards the vital emergence of rapport which sets up therapeutic alliance, and that silences should be seen as an interaction rather than the absence of interaction. I felt silences helped the parents and myself '*re-group'*, especially after emotional experiences, and I learnt to see the *'value'* in them. Therefore, I decided to write the silences into the dialogue of my stories because I felt this added to the overall picture of what parents had shared, and allow a reader to see the difficulties and challenges that parents experienced.

Listening

In my role as a nurse practitioner, most of the time parents listen to me perhaps more than I listen to them. When we meet initially, I like to know more about their child and family as it helps me to support them. However, it is then over to me as I talk about a tracheostomy, why their child needs one, the clinical training required and the discharge planning process, care packages and support if needed. As part of this encounter, I deal with parents' questions and concerns. As a researcher, I soon realised that *'role reversal*' takes place. I wrote in my field notes after my second interview that listening '*is hard for me*'. I reflected on how I needed to acknowledge that my research role is different and that it was important to develop my listening skills. Applying the ethical principle of honesty and reflecting on my listening skills, I can honestly say it took me some time to develop these skills. I worked hard to keep myself *'in check'* and it took me some time to feel comfortable with listening and letting parents run with what they were saying rather than *'jumping in'* to explore issues. However, I knew that listening carefully showed the parents my interest in what they had to say. The ability to listen is linked to recognising what is important to the conversation (Canary, Cody, & Manusov, 2000). As I became more experienced, especially in time point 2 and 3 interviews, I became more comfortable with listening and was more able to prompt or explore experiences without interrupting their stories. However, not all parents participated in all three interviews and I have to reflect that I may have missed some opportunities to explore their experiences.

Emotional experiences

Parents' well-being was paramount to me throughout my study. During the interviews there were times when parents expressed emotions and feelings. Parents spoke of their fear, shock, upset and anxiety and some parents cried. It was hard for me to listen to these stories and witness their distress and I hope I dealt with these situations with a caring supportive approach. Emotional storytelling provides the purpose of giving a voice to participants' experiences (Frank, 2001; Wilkinson, 2004), which can be especially important during times of crisis (Denzin, 1989). I reflected on each interview and especially those which were obviously very emotional and my notes record that by the time I left parents they seemed to have composed themselves. I also reflected on how my nursing skills and knowing the family professionally as a nurse helped in such situations, for example, I felt that knowing the medical reason for their child needing tracheostomy and the possible future outcomes was an advantage for me as the researcher. Some parents also commented either during or post-interview that talking was '*therapeutic'* and that they felt better. These reports from the parents made me feel better as it was good to know that in some way talking about their experiences had helped them.

I was not prepared for the emotional impact of transcribing, reading and re-reading, then writing about parents' emotional experiences. It was difficult for me to move away from such experiences and it was emotionally draining. I realised that I had not really fully addressed my own feelings after the interviews had finished, and on reflection I had an unrealistic expectation of how I would manage my own feelings. I think this was down to my typing the parents' words and analysing their stories and '*meaningfully engaging'* in what they had to say, more so than I would have when delivering my clinical role. Some aspects of parents' experiences were hard to listen to, for example, one father talked about his emotions when signing the consent form for his son's tracheostomy, and there were many other examples when the parents' described how their initial experiences with their child were overwhelming. Easterling and Johnson (2015) note that it is of the utmost importance that researchers openly discuss emotional issues, and this is further supported by Arditti, Joest, Lamber-Shute and Walker (2010), who suggest that awareness of emotions helps researchers grow. I had the support of my supervisory team who helped me talk this through. I realised that this was part of what parents wanted to tell me and it was important for me as a researcher to interpret the stories and do justice to them for the families.

I never knew that?

One of the most surprising aspects of being a researcher was my realisation that parents do not always share some of their key experiences with me as a nurse practitioner. There were several times in interviews when I thought *'I never knew that'*, and I realised that maybe this would have helped me support and help the parents more as their nurse. One such time was when Jack's mother revealed that she had already lost a child who was premature and because of this she was emotionally scared about having to go through that pain again. This was something she had not shared with me as a nurse practitioner. It made me realise that I can never fully know just what the parents I am caring for go through. It also emphasised the importance of spending time with and listening to parents in my role as a nurse-practitioner in order to give them the opportunity to reveal important information I might otherwise miss. As a researcher I had this time, and I wrote in my field notes how I felt that I had really *'heard'* Jack's mother's experience that day. I thought about what she said long after the interview had finished and I realised that at times as a nurse I do not always have the time or ask the right questions. I realised that I should be trying to do this aspect of my role better.

Signing off

After each interview, I took the time with parents to provide an opportunity for discussion, feedback and debriefing. There were situations when parents continued to talk and I asked if I could put the audio recorder back on, as I felt it was important to record what they were saying. All the parents agreed to this. In particular, I remember the ending of an interview with Louise's mother, who had talked about her other daughter who was a teenager and the impact that her sister's complex needs had on her. Once this interview had finished we both started to talk about our daughters, who were the same age, and the challenges of being a parent of a teenager. We chatted for quite some time about the pros and cons of this age group and left each other with laughter about how untidy they are. On reflection, I felt that this helped us to disengage from the interview. I felt like '*sharing this part of me'*, which typically I would not do as a nurse, was beneficial to both of us that day.

Reflections on data analysis

When I reflect back to how I looked at and started to analyse my data, '*I smile'*; what I planned never happened (as predicted by my supervisory team). I was completely unprepared for all of the data that I collected and initially I was overwhelmed by it. Irvine and Gaffikin (2006) note that qualitative researchers face challenges when sorting out of large amounts of data and arranging the data without losing its richness. I felt I needed some structure to help me cope and I used a technique called OSOP which I learned about on a data analysis course. I remember the look on one supervisor's face when I produced what felt like my 100th OSOP; the look alone made me decide that I needed to rethink the way I was approaching my analysis. However, on reflection, although the OSOPs did not survive to the end of my analytical approach because my thinking and recognition skills had shifted, they did serve as a useful tool at the outset, allowing me to bring the data together in the initial stages, and this was helpful.

My plan in the first instance was to use thematic narrative analysis, something I had come across from my reading. The problem that I encountered using this method was that it was not allowing me to find the richness in my data and "dig deep" and do what my supervisory team said was to '*make my data sing'.* I also had issues with my thinking and interpretation skills as I was using my clinical head rather than engaging my researcher head. This took me some time to adapt to and this was reflected in my interpretation of the data. For some time, I would think I had some strong stories, but my supervisory team would *say 'you have some lovely data*' but note that it needed deeper analysis and it needed to be approached conceptually as a researcher.

After one meeting with my supervisors we had discussed Frank's socio-narratology, something I had looked at early on but had discarded as it seemed too complex for me as a novice researcher. By the end of the meeting I was encouraged by my supervisory team to look at this again, even if all I did was to apply Frank's (2010) "*story telling questions*" and dialogical narrative analysis to a few transcripts. However, I will never forget that evening, and rather than just apply this approach to a few transcripts I applied it to all my time point one interviews. The day flew by and I knew then that '*something had changed'*. I was starting to make my *'data sing'*; I was growing up as a researcher. One of my supervisors on feedback wrote that she '*danced round the room with glee*'. On further application of this method it was apparent that this was what my data needed; *'I have never looked back and have continued to learn'*.

Summary

In conclusion, this chapter has presented the methodology and methods used within this study and a rationale for decisions made. The research methodology used in this study was a qualitative approach. Narrative inquiry is presented in this chapter as the chosen method to explore the experiences of parents whose child had a tracheostomy. Particular attention has been given to how I developed a study that is robust, ethical and protects the parents. Narrative interviews were the chosen method of data collection and a socio-narratology approach (DNA) has been applied to the data in order to explore parental experiences over the first year of their child having a tracheostomy. I have presented some of my reflections and have been mindful of my actions and my position from within this study. In the next chapter I present vignettes of the families so as to present them in some context and allow the reader to get to know them.

CHAPTER 4: FAMILY VIGNETTES

Introduction

Vignettes have been used in research studies to explore viewpoints, perceptions, beliefs and awareness in real life experiences (Schoenberg & Ravdal, 2000; Taylor 2006; Spading & Phillips, 2007). However, I chose vignettes as an approach that would permit me to present insight into the parents who took part in this study and their children.

My reflections and field notes were instrumental in creating the vignettes. At all times I was aware that maintaining anonymity was paramount, so any data or specific details that could identify a child or their family were removed from the vignettes. All the parents, children and family members were given pseudonyms. Each vignette portrays the mother, or the mother and father when they were interviewed together. The storied approach to the vignettes is line with my narrative approach to my thesis and it covers all the time points when the parents were interviewed.

Table 7: Outline demographic data of the families

Name	Child's age at time of tracheostomy	Medical conditions
The Greene family: Tom, his mother and father and one sibling	6 weeks	• Small airway • Cardiac problems • Feeding issues • Di George syndrome
The Smith family: Rose, and her mother and father and one sibling	4 months	• Cardiac problems • Cleft palate • Large tongue • Feeding issues
The Jones family: Sam, and his mother and father	2 years	• Cerebral palsy • Complex neuro disability • Feeding issues
The Carr family: Melody, and her mother and father	3 months	• Multiple system abnormalities • Small jaw • High palate

The Maguire family: Matthew, and his mother and two siblings	4 weeks	• Laryngeal cleft
The Doyle family: Freya, and her mother and father and one sibling	3 months	• Bilateral vocal cord paralysis
The Crabtree family: Louise, and her mother and father and one sibling	11 years	• Complex neurological condition • PEG feed • Epilepsy • Learning difficulties
The Johnson family: Jack, and his mother and father and one sibling	9 months	• Prematurity of birth • Subglottic stenosis • Chronic lung disease
The Craig family: Anna, and her mother and father.	4 weeks	• Pierre robin syndrome

In the next section, I present each individual family vignette.

The Greene family: Tom, and his mother and father

This mother and father participated in all three interviews, sharing their stories with me, recalling stories from the moment Tom was born with breathing difficulties, and their experiences of the first year of his life with a tracheostomy. The Greene family's home was a long way from the hospital. It had been a considerable journey for them to travel to receive the specialist care required for their son. Tom was their second child and they had another child, Sarah, who was five years older than Tom. Tom's parents chose to be interviewed together.

The first interview took place in a quiet location away from the hospital. They brought Sarah with them and she happily played with her toys. Tom, aged two months, was still an inpatient at this stage, and had been at the specialist hospital for several weeks, although going home was on the horizon. Tom's father had said prior to the interview that he would be present at the interview to support his wife. However, throughout all of the interviews he shared his experiences and made important contributions to the study, particularly about the times when the stakes were "*high*" for Tom and for the family. During the first interview Tom's father became emotionally upset, especially when recalling the time when Tom was born and the "*unexpected shock*" of seeing Tom with breathing difficulties and then facing the need for his son to have a tracheostomy. Tom's mother described her life as a mother who had not been prepared for the "*shock*" and "*devastation*" of her son's birth and subsequent complex diagnosis. At the end of the first interview she described how recalling all of the events throughout the interview had helped her to remember and feel the "*relie*f" and "*freedom*" again, now that Tom had his tracheostomy and was out of danger. She felt it was good to talk and she explained that talking about it "*frees you up*".

As I travelled to the Greene family home for the second interview, I was really looking forward to seeing how this family was getting on. Tom's mother appeared happy and relaxed as she made me a cup of tea and made me feel comfortable in their lounge. Tom's father had gone to work earlier but was taking some time off to come for the interview. I felt really appreciative that he would do this. He said he felt it was important to make the time, and he arrived 10 minutes after me. Both parents complemented each other throughout the interview on their thoughts and feelings about their experiences at home and were happy to speak freely together. There seemed to be a shift in their experiences from the emotional turmoil of facing a tracheostomy, to emotions that were more settled, and they talked of being "*grateful*" and "*confident*" with Tom's tracheostomy. Tom's parents firmly believed that "*just because he breathes differently*" should not matter to Tom in his everyday life. Tom's parents focussed on his positive achievements and were happy that his health was "*improving*" and they shared photographs of Tom with me.

When I rang to arrange the third interview, Tom's mother told me that they were coming to the hospital for a clinic appointment soon and would be happy to meet with me near the specialist hospital. I arranged a quiet location for us to meet. Tom and his parents were already there when I arrived and Tom was walking outside in the garden. It was immediately clear to me that the baby who had previously had to fight for his life was now 12 months old; a strong toddler, with his own personality. I could see how much he had grown and developed between each visit. Tom's parents talked of how the year since Tom's birth had been "*unexpected*" and a "*different journey*" from what they had expected, with a lot at stake, but both parents were very positive about the future. In the face of adversity they had "*faced their fears*" and, as his mother described, "*Tom is Tom*" and they love him the way he is.

The Smith family: Rose, and her mother and father

The Smith family lived locally to the specialist hospital. When it was decided that Rose needed a tracheostomy aged four months, she had already been in hospital for several weeks and had had numerous operations. Rose's mother was on maternity leave and she travelled to the hospital every day to be with Rose, once she had taken William, her oldest child, to school. Rose's father had taken time off work when Rose was critically ill but was now back working. The family's life was centred on being at the hospital as much as they could. My first interview with Rose's mother took place at a quiet location away from the hospital.

Rose's mother was surprised that the interview was very emotional for her. She shared her feelings with me at the end of the interview, saying, "*I didn't think I would cry*". In recalling her experiences she shared her feelings and fears about her daughter having a tracheostomy. She talked about having to face her fears and her eventual acceptance of Rose having a tracheostomy even though she questioned "*Why Rose?"* especially as Rose had been through so much surgery and ill health. She explained that while Rose has some "*disadvantages*", she is "*ours*" and she is "*special*". Rose was in hospital for a lot longer than expected after she had her tracheostomy due to other health complications and it was several months before she was discharged home.

It was not until late autumn when Rose's mother opened the door to her home and welcomed me into the lounge for our second interview. Her home was quiet and still and there was a warm feeling to it. Rose was sitting in her chair, playing with some toys; she gave me a lovely welcome and a shy smile. Rose was now one and what struck me the most was how long her hair was. As we started the interview it was nice that Rose was there, it added extra feeling to the interview. We talked about how well Rose was doing, and it was hard to imagine how poorly she had been.

Apart from needing to be suctioned a few times, which is normal for a child with a tracheostomy, Rose was quite content. Rose's mother spoke about how her working life had been put "*on hold*" and how she was now at home looking after Rose full time. Rose's mother was more relaxed compared to her previous interview as she shared her experiences with me; in particular she was excited to have "*gone away as a family*" for a few days and this had been "*great*". She discussed how her son William had been very "*protective*" of his little sister. Rose's mother was someone who seemed to always try and look on the positive side of things.

The third interview took place at the family home around 16 months after Rose had had her tracheostomy. This was due to a few hospital admissions Rose had had since we last met. The last one being due to a tracheostomy related issue, so we discussed how this was going before the interview got underway. Rose again was present and was quite happy listening to us or sleeping on her play mat. Rose's mother spoke movingly about Rose's future and her desire that the tracheostomy was "*not forever*" and the fact Rose had another big operation "*coming up*", describing this as another one "*off the list*". We focused on how well Rose was developing even though there had been setbacks and some hospital admissions. Rose's mother was convinced that the future would be "*bright*" for Rose and that in the not too distant future Rose would have her tracheostomy removed.

The Jones family: Sam, and his mother and father

Sam's parents chose to be interviewed together. Sam was their only child, who needed a tracheostomy when he was two years of age. His parents shared a very emotional story about Sam's traumatic birth and his father referred to this as "*midwifery negligence*". Sam's father took the lead in this interview and he openly acknowledged this, although at times he did try to let Sam's mother contribute. His passion for his son and the journey that they had faced with Sam's health issues was moving. In fact, listening to this father made me realise what a great storyteller he was and I reflected on this afterwards with Sam's mother. She was delighted to be part of the study and thought it was important for them both to tell me about their experiences. She was happy that she had shared what was “important” to her. She shared one particular moment about her reluctance to do a tube change that I recalled as a clinician, as she remembered’ “*I kept trying to put it off*”, although on recalling this she laughed at how silly this now seemed.

One of the main issues for both parents was that they had been very “*against*” Sam having a tracheostomy, thinking it was “*the end of the world*”. They told of the long journey that they had had as a family in and out of hospital with “*lots of admissions*” with Sam having feeding issues. They also talked about how Sam’s breathing, which they felt was “*normal*”, became an issue that had concerned the doctors. By the end of the interview, they both shared how it was helpful to chat with me as a researcher and that in some way, talking about their experiences had contributed to some of their acceptance, and moving forward to the future and thinking about taking Sam home.

Sam’s father gave me a warm welcome for the second interview and he invited me into their living room and offered me coffee. It was lovely to see Sam, who was smiling at me and appeared happy with the attention I gave him. Sam’s parents were delighted to be home and they informed me that there had been no “*hospital admissions*” since Sam’s discharge. Sam and his parents were relaxed and happy and this was wonderful to see; they both talked about being “*confident*” in managing Sam’s tracheostomy. Sam’s mother and father asked if I would like to see Sam’s new bedroom. Sam’s father had been off work and had been decorating it for most of the day and he proudly showed me his son’s room that had been decorated in true boy style fashion. The room was mainly decorated in blue, which triggered a brief chat about football as Sam’s father and I supported the same local team. We then all settled down along with Sam to start the second interview.

The third interview was again at the family home and when I arrived Sam’s father invited me in. Sam’s mother was just finishing getting ready; I could hear the hair dryer. Sam’s father offered me coffee and we chatted while we waited for Sam’s mother. He told me that Sam had been a little under the weather. He shared with me that he had taken a “*career break*” to help with Sam because juggling work with Sam’s care demands had become hard to deal with. He spoke about how this pressure had helped him to decide that "*home life*" was more important than anything else. We also discussed some issues with equipment and consumables that I promised in my role as a clinician to sort out. When Sam's mother joined us we settled down for the third interview. Sam's father discussed that Sam having a tracheostomy had been the best option for his son and seemed more accepting of a tracheostomy 12 months on. However, both parents spoke about hoping that one day the tracheostomy would be removed and they described this day as "*Shangri-La*".

The Carr family: Melody, and her mother and father

Melody's mother's first interview took place a few weeks after Melody had her tracheostomy at three months old, whilst Melody was still an inpatient. We met up in the foyer of the hospital and I had booked a quiet room for the interview. Melody's mother recalled the story of Melody's birth with a mixture of emotions. Melody was her first child and the birth had been "*sudden*" and "*traumatic*" for them both. Melody was born at the local district general hospital and had been admitted straight to the special baby care unit. Her mother remembered how she was separated from Melody at the birth and the "*emotional upset*" this has caused her. The local health care team in the special baby unit deemed it necessary for Melody to be transferred to a hospital several miles away for specialist paediatric care. Melody's mother remembered the "*battles*" she had to get there and see her daughter. She also realised that she was ill herself and she spoke about how this impacted on her, although her main concern was that Melody was alright. She spoke about how her experiences had made her "*stronger*".

I travelled to see Melody's mother for the second and third interview at the family home in a small village in the heart of England. I was welcomed into the home both times by Melody's mother; Melody's father worked away from home. Melody's mother was and had always been "*positive*" about her daughter having a tracheostomy and viewed it as having saved Melody's life. In both these interviews she stressed how her "*confidence*" and her "*ability*" to care for Melody had grown. She spoke about how her working life had "suffered" because of Melody's extra needs. However, she was determined to give her daughter as "*normal*" a life as possible and discussed taking her to playgroup. She also discussed her "*distressing*" experiences about people's reactions to Melody's tracheostomy. A year after Melody had her tracheostomy, her mother was grateful that Melody was developing and thriving and she saw each day as a "*blessing*".

The Maguire family: Matthew, and his mother and father

The first and only interview with Matthew's mother took place near the specialist hospital, which was far from the family home. Matthew's mother was missing her other two children, who were under ten years of age and being looked after by their maternal grandmother. Matthew's mother was very shy and reserved upon interview. I felt at the time that this was my most challenging interview because it was difficult at first to draw out her feelings. However, on reflection and subsequent reading of the interview she contributed important data to the study by revealing her fears of a tracheostomy for Matthew. She talked about Matthew's birth and the "*very scary*" events that unexpectedly had evolved around her and described her feelings of being frightened for her son. Her bravery, at times, was heart rending and, as a researcher, I saw vulnerability in her that I had not seen as a nurse practitioner.

She spoke openly of her desire to bond with Matthew and for him to be a "*normal*" child. Once she started to talk about this and how she made decisions so that he could be a normal child she appeared to talk very happily. She described her son's personality and said that he was a "*cheeky monkey*" especially when she was learning to do the tracheostomy cares. We both laughed at this because as Matthew's nurse practitioner I too had had difficulty doing his tapes. When I rang Matthew's mother for a second interview she said that talking into the tape recorder had been difficult for her to do. I did offer her a telephone interview, which at first she seemed happy to take part in. However, after two more attempts to contact her when she never replied to my messages, I did not contact her any further.

The Doyle family: Freya, and her mother and father

When I arranged to see Freya's mother for our first interview she was particularly happy as a discharge date had been set for Freya to go home several weeks after having a tracheostomy. Freya was the second child and her mother described her as a “*very naughty baby*” because her experience of her birth and subsequent breathing issues had been totally different to Darcy, her other daughter who was now at primary school. Although Freya’s father worked away from home, he was trained to be clinically competent to care for his daughter’s tracheostomy, Freya’s mother was happy to be the “*main carer*” at home. She was easy to listen to as she told me about Freya’s birth and the “*uncertainty*” and “*shock*” of Freya’s breathing issues. She discussed her “*annoyance*” with the local hospital and how they kept important information about Freya from the family. During her storytelling she remained calm and contained her emotions. She expressed feelings of sadness and talked of how it felt “*horrible*” that Freya needed a tracheostomy. However, her acceptance of a tracheostomy for Freya was almost immediate. Freya stopped being a “*very naughty baby*” because her breathing issues settled and became “*cheeky*” like her sister. Her mother expressed feelings of being grateful for the tracheostomy as it had saved Freya’s life and talked about being very hopeful for the future.

I travelled to Freya’s home for the second interview. Freya’s mother opened the door and welcomed me into the front room, Freya was asleep and the house was silent. We sat down, with a cup of tea and some biscuits and Freya’s mother told me about her busy morning. Freya’s mother was delighted that Freya was doing well and that they had settled into a “*good family routine*” and how she remained positive. She described her family as “*very helpful*” and a constant support to her and she talked very happily about the future. She described the difficulties with Freya’s father working away, in particular now that Freya had a tracheostomy. However, once Freya’s tracheostomy had been taken out, the family was planning to live nearer her husband’s work commitments.

The third interview was arranged and Freya’s mother was happy for me to go again to the family home. She remained “*positive*” about the future and was happy that her daughter was “*doing so well*”. Freya’s mother seemed extremely independent and proud of her achievements and of how well her daughter was doing. She talked about how “*grateful*” she was that the tracheostomy had saved Freya’s life and talked about all aspects of her “*routine*” at home and how hopeful she was for Freya’s future.

The Crabtree family: Louise, and her mother and father

Louise had been in hospital for several weeks in intensive care and high dependency units before she had a tracheostomy. Louise was a child with unique special needs from birth and was now over ten years of age. Louise's mother described herself as a mother who was a "*special needs mum*" to a child with complex issues, and she had an active international role in supporting other parents whose child had similar needs. She describes her relationship with her other daughter as "*close*" although she felt guilty at times because Louise takes up a lot of her time. In her first interview with me she told me a story about how she faced her fear when she realised that Louise needed a tracheostomy. She recalled how she had never wanted a tracheostomy for Louise and had hoped that she would never have to "*face it*", but how, when faced with her child needing a tracheostomy she "*moved the goal post*" for the sake of her child. She talked about aspects of her life and family life that had been put "*on hold*" while Louise had been in hospital. She discussed the impact of Louise having a tracheostomy and how this had affected Louise's sister. She talked passionately about the lack of support for siblings who are faced with a sister or a brother who needs a tracheostomy.

When I rang Louise's mother to organise our second interview, she chose to be interviewed away from the family home as it was a "*busy place*". She informed me that she was doing voluntary work now at the specialist hospital one day a week and would be happy to meet me after she finished work. I arranged for a quiet place for us to meet, and she told me about her work at the hospital and how this was "*her time*" and how she wanted to give something back. She had applied for direct payments so that she could set up a care package for Louise and she reflected on this, and how she wanted to be part of the interview process to recruit for carers to care for Louise. She talked about how hard it was to find the "*right carers*" and how hard it was for them as a family to leave Louise with just anyone. She talked about how care for Louise was juggled between her and Louise's father, who worked six days a week to support the family. Louise's mother also talked about how Louise had continued to have some hospital admissions since her tracheostomy. She believed that since the tracheostomy there was "*less time spent*" in for each admission and the impact on Louise had been reduced considerably. It had been a long day for Louise's mother and by the time the interview had finished she was looking forward to going home to her family.

The third interview was arranged similarly to the second interview, with Louise's mother meeting me at a time and place that was suitable for her. She was very fed up when we met as her care package had gone "*belly up*" again. She just could not find an appropriate "*tracheostomy trained carer*" and the impact this had on her and Louise and was frustrating. However, she acknowledged that she continued to feel "*relieved*" that the tracheostomy had changed Louise's life, making her more stable with her breathing. However, she was uncertain about how she would cope without a care package in place and she talked about this as being the "*down side*" to the tracheostomy.

The Johnson family: Jack, and his mother and father

The day I interviewed Jack's mother, she had just come from seeing Jack on the ward and had already had a busy morning taking her older daughter to school. Although Jack's family had not lived very far away from the specialist hospital, lack of transport and wanting to be near Jack meant they had moved nearer the hospital. Jack's father worked twelve-hour days to support the family, so Jack's mother felt that she was the main "*carer*" for Jack's health needs. Accepting a tracheostomy for Jack was hard for her, but she did believe strongly in her faith and God. At times throughout the interview she became very emotional. However, she was "*grateful to God*" that he had given her doctors and the nurses with the skills to care for Jack and to save his life. She shared with me a story about her past pregnancies, something I had never picked up on in my clinical role. She talked about her previous experience of having a premature baby who had died and this added to her "*worry*" and her "*fears*" about Jack surviving. These were experiences that she shared with me and this had an impact on me. Reflecting on this later, I realised that even though as a nurse practitioner I try and ask families to tell me their stories when I first meet them at the bedside, there are always 'hidden stories'.

The second interview took place five months after Jack had his tracheostomy surgery as his health needs and the decision to apply for a care package had kept Jack in hospital a lot longer than expected. It was a sunny June day when Jack's mother opened the door to her home and welcomed me in. They had been home for nearly three months. She offered me coffee and brought Jack to see me. I was quite shocked to see how Jack had grown. Smiling and giving me a cuddle, I was overwhelmed and happy to see him. Jack's mother made me coffee and we settled down for the interview. She spoke movingly about how happy she was that her son was "*doing OK*" and that it was "*great*" to be at home. The support of the care package was important to her as she had worried about the impact his tracheostomy needs would have on the "*family*" and "*going out*". Going out was a concern for Jack's mother and the worry of this was apparent. As the interview was drawing to a close she talked about how "*encouraged*" she was that Jack was doing well, and that the tracheostomy had "*saved his life*".

I arranged to see Jack's mother for the third interview at the family home, and as I parked my car I reflected on how although this was not the final family in my study this was my last interview for the study, and this evoked mixed emotions. Jack's mother happily greeted me into her home and she made me feel comfortable in her front room and then made some tea. Jack's mother told me how "*disappointed*" she was with the care package that she was receiving and how the support she had was "*just not enough*". She hoped that this would be increased in the future because she was tired of not getting "*enough sleep*". However, she was happy with Jack and hopeful for the future.

The Craig family: Anna, and her mother and father

Anna's parents were happy to be interviewed together. Anna was still an inpatient on the ward at the time of the first interview, but discharge home was not far away. A local family, Anna was their first child and in their only interview with me they both recalled vividly the "*shock*" of Anna's breathing difficulties from birth. The need for their daughter to have a tracheostomy was "*scary*" for them and they shared stories of how they had felt the strain of Anna needing a tracheostomy. They told stories of how "*unexpected*" this was for them and how they had never previously heard of Anna's diagnosis or a tracheostomy. However, they faced their fears, and spoke movingly about their worry of how Anna must have been feeling and how "*guilty*" they felt about this.

Anna's father recalled how he had had a heavy cold the day he was supposed to do his first tube change and about how he was "*very nervous*" about doing it. Due to his worry about passing his cold on to his daughter he stayed out of the way "f*or a few days*" and delayed doing his first tube change. Anna's mother talked about how well Anna was doing and how she had come to terms with seeing Anna with a tracheostomy as she realised that it had "*saved her daughter's life*". Both of Anna's parents were happy to be part of the study but due to social issues that occurred a few weeks later they were no longer eligible to continue to contribute to the study, but they consented for their interview data to be used.

Conclusion

This chapter has presented the families' vignettes, to familiarise the reader with each family's circumstances. This leads on to the next chapter, which presents the findings of what parents shared with me about their experiences.

CHAPTER 5: FINDINGS

Introduction

This chapter presents the findings from the interpretation of the stories told by the parents within the first twelve months of their child having a tracheostomy. These findings are encompassed within a meta-story, ‘Going with it’, and two core stories and other sub-stories. All these stories are presented in this chapter.

‘Going with it’: the meta-story

‘Going with it’ – the meta-story - includes the parents’ early experiences of their child’s breathing problems and how they lived through difficult times because they had no control over what was happening to them and their child. They had no choice but to ‘go with’ the situation that they found themselves in. However, after surgery to form a tracheostomy and when a degree of control was re-established, the parents told stories reflecting a realisation that the tracheostomy had saved their child’s life and that ‘going with it’ had been the right thing to do. All these experiences challenged and changed the parents’ perspectives on their child having a tracheostomy.

‘Going with it’ was associated with the parents experiencing distressing times. For instance, parents had to ‘go with it’ when they faced their child’s medical diagnosis and the need for a tracheostomy which they found shocking and upsetting. Facing the day of surgery, and the risks of surgery to their child along with the impact of their child having a tracheostomy were other causes of distress for the parents. ‘Going with it’ was also associated with parents talking about how life was different after they had got through the initial upset and impact of their child having a tracheostomy. As the parents became more confident and less apprehensive about aspects of their child’s care, life with a child with a tracheostomy became easier and they were more capable of being able to ‘go with it’ and face new experiences in their everyday lives so that they were hopeful for the future.

The meta–story ‘going with it: is composed of two core stories (see Figure 5.1):

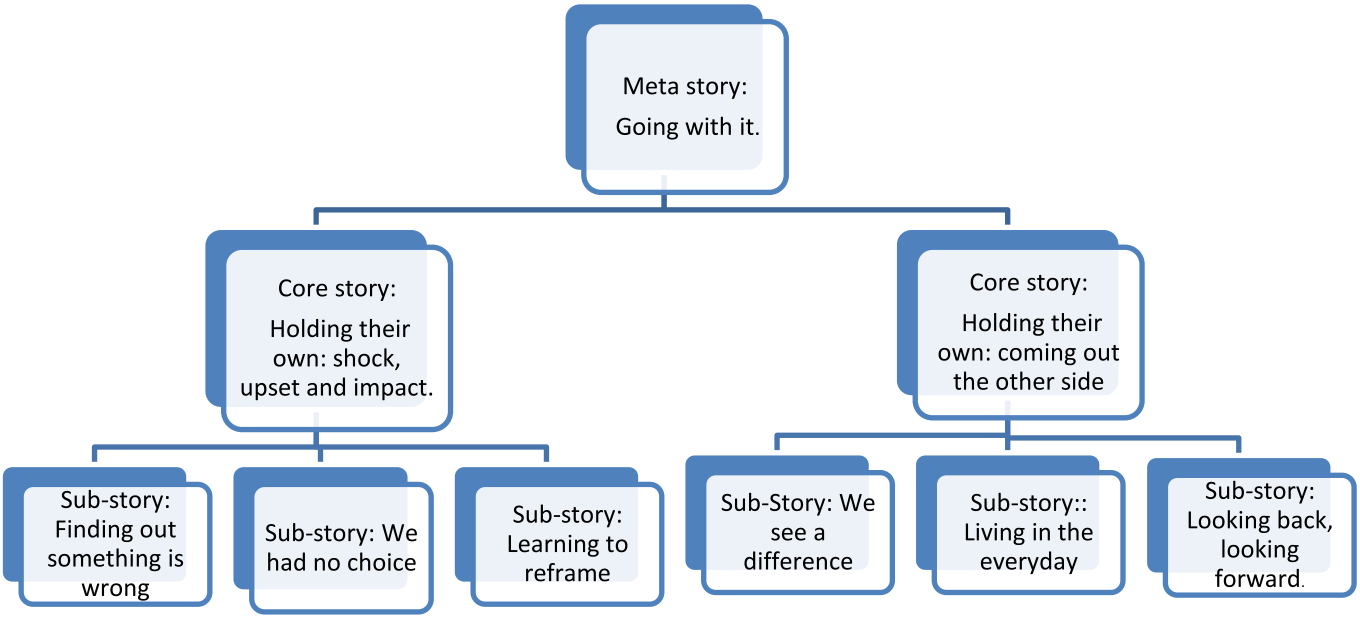
- Holding their own: shock, upset and impact.
- Holding their own: coming out the other side.

The notion of parents ‘holding their own’ was an element that ran through all the stories that they told. Most of the parents experienced the unexpected shock that their child had a breathing problem. Core to the parents’ experiences was a sense of them having to hold their own in difficult and upsetting times when their child was facing life threatening illness. During these difficult times, the parents felt tested. However, they showed the capacity to recover when the threat to their child’s life had resolved. Over time parents became stronger and were better able to ‘hold their own’ as they learnt to ‘deal with it’ practically and psychologically.

Each core story was supported by a sub-story which presents the parent’s stories about specific key events. The core story, ‘Holding their own: shock, upset and impact’, is characterised by parents finding out that something was wrong with their child, the need for their child to have a tracheostomy and how this impacted on them and their child. The core story, ‘Holding their own: coming out the other side’, is characterised by the parents seeing a difference in their child, getting into everyday routines at home, living in their everyday routines, and reflecting back on their experiences and towards their hopes for the future.

Time point 1 (TP1) indicates the early stories told by parents. Time point 2 (TP2) indicates the stories told by parents after being home three months onwards and timepoint 3 (TP3) indicates the stories told by parents twelve months after their child had a tracheostomy.

Figure 5.1: Meta, core and sub-stories of parent's experiences of having a child with a tracheostomy.



Core story: *Holding their own: shock, upset and impact*

Introduction to the core story: '*Holding their own': Shock, upset and impact*.

This core story includes stories that illustrate the parents' experiences of when they were 'holding their own' during challenging times. Many of the early stories revealed situations in which the parents were frightened and anxious and had to deal with inner turmoil. Initially these situations were often associated with their child being hospitalised due to breathing problems, which led the parents to face an uncertain future for their child. The stories reflected their worry and response to their child's unexpected medical diagnosis and the need for a tracheostomy. Parents recalled their journeys to seek help for their child and the places these journeys took them when their child was struggling to breathe and hold their own.

Most children had breathing difficulties from birth and required a tracheostomy fairly quickly, whilst other children developed breathing problems and the need for a tracheostomy when they were older. However, all the parents had faced unexpected shock and chaos when they realised that their child's breathing was not normal and they needed a tracheostomy. The parents also had to deal with their own concerns about the impact a tracheostomy would have for them and their child. Within these stories the parents learned to care for their child's tracheostomy and deal with peoples' responses to their child's tracheostomy. Parents also talked of 'holding their own' once discharged home, and these stories are full of the mixed emotions felt during the early days at home with their child with a tracheostomy.

The core story is composed of three sub-stories 'Finding out something is wrong', 'We had no choice', and 'Learning to deal with it'. In the following sections, these sub-stories are explained in more detail.

Sub-story: *'Finding out something is wrong'*

The sub story 'Finding out something is wrong' describes the times when parents faced uncertainty because their child had breathing issues and were uncertain what the problem might be. The most intense period for parents occurred when they initially found out something was wrong with their child. This plunged parents into periods of shock. Parents told stories about the moment when their child was born and how they experienced immediate breathing problems and how this forced the family into situations and places they were not expecting to encounter. Three families recalled their child having breathing issues not long after birth. Matthew's mother remembered that, "*He sounded like he was singing"*. Tom's parent's spoke of the unexpected medical activity at Tom's birth and their fear for their son's life from the instant he was born. As Tom's father explained:

> "*And it was the worst thing as you were not made aware that he had any issues whilst he was in the womb. The moment he was born they had a respiratory table there in the room. So he was on there for 45 minutes surrounded by about 6 or 7 doctors. We didn't hear him cry or make any noise 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 - TP1)*

Expressing how fearful she had been about what was happening to Tom his mother recalled her feelings when he was taken away:

> "*[They said] 'We will speak to you as soon as possible,' so that was it and we sat there watching them do all this to our brand new baby and really not knowing what's going on.*" *(Tom's Mother - TP1)*

Anna's mother talked about a similar experience at her daughter's birth as she remembered her worry about Anna's breathing:

> "*She had breathing difficulties from birth when she first came out. I was saying 'She can't breathe'. The midwife said, 'Just blow on her face'. So I was blowing on her face and it was like making her breathe. Then I was looking at her and I must have dozed off and when I woke up her legs were in the air and it looked like her chest was touching her back. So I went out and got the midwife and she came in and pressed the bell and the doctors came in and whizzed her off […silence…].*" *(Anna's Mother - TP1)*

Although some parents found out that their child had breathing issues straightaway, other children developed problems after a period of time. For three parents the realization that something was wrong with their child's breathing arose once they were home. Two families were discharged home from the maternity hospital with babies who had undetected airway issues. Jack's mother recalled finding out what the problem was with Jack's breathing:

> "*The baby came 26 weeks 4 days, so they put him on a ventilator down his throat and that caused a scar in his throat. In the hospital where he was born, I don't think they noticed it. When we went home we stayed at that hospital for 3 months. He was doing alright, so after 4 weeks when we got home he was breathing abnormal like panting. When he was active you would see him panting like he had run a marathon or something. So I brought him here [specialist hospital] and they said, 'It is floppy larynx, so*

> *he is going to grow out of it'. But the midwife came and he was doing this so she said, 'We should bring him back for proper investigation'. So when they did a scan they noticed the scar. He had blocked the airway like 75% of his airway was blocked so he was breathing from 25% and that was making him struggle and make that noise.*" *(Jack's Mother - TP1)*

Freya's mother recollected her annoyance when she was not made aware of her daughter's medical issues. She had not known what was *'at stake'* when they took Freya home:

> "*When she was 5 ½ hours old, she had seizures in the cot. We were just about to go home. They didn't know what had caused it, so they took her to the neonatal unit. She kept on having a seizure and was like that for about three hours, so they put on some medication that made her really sleepy. They said, 'She wasn't breathing properly by herself'. So they vented her, they didn't tell us that they were venting her and we were very annoyed about that.* ***.*** *Because when we actually got her home we had a discharge letter that said one of the seizures that she's had lasted seven minutes and we didn't know, they didn't tell us. And that one of the CT scans she had showed she'd had a little bleed on her brain and they didn't tell us that either. This arrived in a letter and made us feel very very annoyed, a bit scared because obviously we didn't know so we brought Freya home really unaware what had actually happened. They just sent us home and told us that she had noisy breathing and would grow out of it. They then gave us the appointment to come here so it was a bit unknown." (Freya's Mother - TP1)*

Sam's parents had managed Sam and his breathing issues at home for over 12 months, before realising something was wrong. Sam's father recalled that his son's breathing had "s*ort of distorted the shape of his chest because of this effort that he was having to put in".* Sam's parents had not realised his breathing was abnormal or that he was in danger, as his mother explained:

> "*We thought it was normal, that's fine that's just Sam, the way he breathes, not knowing that he was struggling. It's mad mad.*" *(Sam's Mother - TP1)*

Sam's father recalled talking about his son's breathing to professionals:

> "*Yeah yeah we would mention his stridor to the doctors, they would say, 'That's normal', and for twelve months we sort of lived like that.*" *(Sam's Father - TP1)*

Sam's mother described how the consultant "*looked pretty solemn*" when he confirmed that Sam had a breathing problem and said, "*No it's not right, something needs doing*"*.*

A key concern for three of the parents was the uncertainty about their child's breathing and not knowing what was wrong with their child. As Tom's father explained, "*we were none the wiser*" after Tom had been taken to the special baby care unit. Furthermore, parents told stories about the effects the uncertainty had had on them and the need to seek medical help. This was an intense period of time for the parents as they experienced a roller-coaster of emotions. Anna's mother described the turmoil she experienced when seeing her child struggle with breathing and how this made her insist that Anna needed specialist help:

> "*Then they had a little tube just in her mouth. She was taped up for three days and like they kept putting her on her back and she was crying and she was struggling for them three days. That's why I was telling them, 'She needs to go to specialist paediatric hospital, she needs to go to specialist paediatric hospital and see somebody'. So obviously they didn't know she needed a trachy, till she came here. So the hospital where she was born didn't know [….silence …]*" *(Anna's Mother - TP1)*

Tom's parents told a compelling story of their journey to seek medical help for Tom. Despite Tom's father feeling in the dark as to what was wrong with his son, he knew that the medical team, where Tom was born, were doing all they could:

> "*They took him to a special care unit, we were still none the wiser. The doctors knew he was having breathing difficulties, they [doctors] couldn't understand. They were checking his airways, checking his heart, doing all they can. We knew they were doing all they can […silence ….].*" *(Tom's Father -TP1)*

Tom's mother described her fears when "*we went down to the special care ward*" and heard the news that her son needed help at another hospital and how this started her "*worrying even more*". Given the significance of Tom's breathing issues, his parents recollected being told that Tom needed a specialist type of help, as his mother explained:

> "*They said to us [at DGH], 'He is going to need to be reviewed by a specialist ENT team, with small enough equipment to see what the problem is'.*" *(Tom's Mother - TP1)*

Tom's father remembered that there seemed to be no time for him to absorb the situation and recalled his fear that Tom might die before he got the right help:

> "*They [doctors] were saying, 'He's got this here, he is in here and we're doing all we can'. However, again no one can give you an answer as to what's wrong. Then you're being told you are being transferred to specialist paediatric hospital, so again it's on the move again and you got no time to think or take it all in. At that point with 7 or 8 wires coming off him and then we were transferred here so those first 3 days was all […. silence….].*" *(Tom's Father - TP1)*

At this point in telling his story he became upset and silent. Tom's mother finished off the story by recalling the travelling and explained there was "*no time even to express milk. There was no time for any of that was there? […. silence………]*" *(Tom's Mother - TP1)*

The shock and upset for parents was reinforced by their child being admitted to the intensive care unit. Being on the Intensive Care Unit forced parents to realise that there was something seriously wrong with their child. For instance, Tom's father's reaction to knowing that his son required immediate intensive care on arrival at the specialist hospital was to think that there "*must be something really bad [wrong] with him [Tom]*". Tom's mother realised something was bad as Tom was getting "*one-on-one care*". Three parents told stories of when they encountered the Intensive Care Unit. Melody's mother recalled the intense activity on the unit around her daughter, "*all the doctors around her and not seeing what they are doing*", but she talked of being "*grateful to the people [health professionals] who have been there to help them*". She went on to explain how as a parent you do not want to be in the Intensive Care Unit and how she was envious of the nurses but knew Melody needed to be there:

> "*It's for the best. But you never want to be there, nobody really sees what goes on behind those doors. They [nurses] sit there all day with them. Even though you kind of feel jealous of the nurse, that they have got a bit more of bond with the baby than you do because they can actually lift them up, touch them. All you can do is sit and hold her hand. […..silence… and mum gets upset I ask her if she wants to stop … silence...] No I am ok. 'Cause you are in there every day, you do see the small changes and you get excited because they open their eyes for the first time or when they are trying to move. She did develop a reputation on ICU the amount of times she has been in and out of there.*" *(Melody's Mother - TP1)*

Tom's father recalled his fears about Tom being on the Intensive Care Unit because he did not know what was wrong with his son. Consequently, he found it difficult to process the information given to him, as he explained:

> "*First time I had ever heard of ICU was when mam [Tom's mother] was taken there. So you start to imagine, 'What's going on? Why you needed such care?' Must be something really bad with him. Again the first couple of days a blur of information and being passed from one specialist to another.*

> *You got family ringing you up asking, ‘What is going on?’. And you can’t give them a straight answer.*” *(Tom’s Father - TP1)*

Other parents talked of their experiences of their child being on the Intensive Care Unit. Anna’s father recalled his feelings of anxiety when he found out that his daughter was on the Intensive Care Unit:

> “*I panicked when I first found out, ‘cause I had come up with me mum in the morning. Anna was already here and I seen those volunteers and asked [where is she], they said, she was upstairs in ICU. I was like mad trying to climb the stairs. You know it was horrible.*” *(Anna’s Father - TP1)*

Anna’s mother realised what was at stake for her child and described the Intensive Care Unit as an intense environment and a scary place. However, she was able to face her fears through the support of staff, she explained:

> “*It was scary ‘cause there were all the other babies and everything like intense. She had a one-to-one nurse. Every time she moved or anything like the machines, I was like, ‘What’s that for’? What’s this for?’. But they explained everything to you and they are really good on Intensive Care, if they even touch her or do anything they say, ‘Look we are going to do this because of this. This is because this happened and that’s because that happened’. The staff on there, to be honest, was really comforting about the trachy and about my feelings and how I was.*” *(Anna’s Mother - TP1)*

Once parents realised that something was wrong with their child, they then faced getting a medical diagnosis. One of the toughest and most emotional times for the parents was when they received the news about their child’s medical diagnosis. They talked about how this news was distressing. Rose’s mother’s reaction to her daughter’s diagnosis was, “*It’s not fair. Why Rose?*”. Most of the conditions the children were diagnosed with were complex and/or genetic conditions which made the journey more uncertain for parents because they were faced with new information. In addition, parents scared themselves further by looking on the internet for more information and this brought the majority of parents more despair. The following quotations convey a sense of what it was like for three parents to receive their child's diagnosis. Matthew's mother remembered the shock she experienced on hearing her son's diagnosis:

> "*They took him down to [theatre] see what his problems were. It was [the consultant], she told us that he had a laryngeal cleft and possible PIG bronchus […. silence….]. At first I felt nothing, then shock and then it took a while and then we googled it. It was life threatening and all that sort of thing […silence…]. I was just upset at first and then I had to get used to it and just hope he'd make it until the operation.*" *(Matthew's Mother - TP1)*

Rose's mother's tone of voice expressed the despair that she felt and her struggle to understand why Rose had complex medical problems:

> "*At first, when we found out I was thinking, 'Why me? Why Rose?'. And then I thought, 'Do you know what? She must be, she has been put on this earth for a reason, she's special, she is mine. So that's the end of it, it's just one of those things.' I did say to Rose's dad, 'Why Rose? It's not fair. Why Rose?' But we just learnt to deal with it now and she is ours and you can't change her […… silence…], sorry [……mum cried ……]. Yeah it's hard […..silence…].*" *(Rose's Mother - TP1)*

Tom's parents were overwhelmed when they received the news of a diagnosis and realised what was at stake for their son, after such a long time of uncertainty about what was wrong with Tom:

> "*He had his endoscopy, is that what it is? [The consultant] basically told us everything that he had found with regards to his jaw being small, his cleft palate nostril being very thin." (Tom's Mother - TP1)*

Tom's father recalled how he was overcome with shock on receiving his son's diagnosis:

> "*They thought he was Pierre Robin at first, just hit us with all this information. This is my findings, this is what we are going to look at, and this is what could happen in the future. It's like, 'Wow hang on'. From a couple of days of blurred information then actually sitting down with someone one-on-one. He [consultant] has done an investigation and then you are told, 'He is going need this in a couple of years; he'll need this in a few months, he'll need this operation'. It's like half a dozen operations to your baby. This is the first person who has sat down after a whirlwind couple of days […….. silence ….]*" *(Tom's Father - TP1)*

The devastating impact of this led Tom's mother to use the internet to find out more information. However, she talked of how exploring the internet was of no help to her and only alarmed her further:

> "*So we did the stupid, well I did anyway, to look on Google and terrified myself. Actually when we spoke to the genetics team it wasn't that bad, it wasn't half as bad as we thought it was going to be. Don't trust the internet.*" *(Tom's Mother -TP1)*

Conclusion to 'Finding out something is wrong'

'Finding out something was wrong' was characterised by the parents facing the shock of their child's breathing issues, the subsequent worry and upset of finding out their child's diagnosis, and the uncertainty about their child's future. The next set of stories focuses on the times when parents were first told about a tracheostomy for their child.

Sub-story: 'We had no choice'

When parents were first told that their child needed a tracheostomy it seemed to be something they could not avoid and something that would affect their child's life in a negative way. However, given the significance of their child's breathing issues the only option for the parents was for their child to have a tracheostomy. Once a tracheostomy had been discussed with parents they became distressed and were very much against this for their child. Sam's father described his feelings saying, "*we were very objectionable to a trachy*". However, parents eventually had to accept that the life threatening breathing problems hanging over their child would not go away. Parents had no choice, because their child's breathing issues had not resolved and they faced a tracheostomy for their child; Freya's mother described this as their "*worst case scenario*".

Four parents experienced strong emotions as the thought of a tracheostomy for their child was difficult to comprehend. Sam's parents in particular, were completely against a tracheostomy and had tried alternative options before agreeing to Sam's operation. They talked about a tracheostomy being an unbearable option for Sam, as his father explained:

> "*I mean pre-procedure, so before the operation we definitely did not want it, we thought it was the end of the world didn't we? Very reluctant really to have the procedure and I remember the day before, I thought I was having a breakdown. Mum had to come up to the hospital. I was with Sam. You had to come up didn't you? I was that upset and I was emotional about it. And the biggest thing that was upsetting me at the time was him losing his voice, not that he is verbal or talks but his cry and his little giddies; [voice] losing that was the most upsetting thing.*" *(Sam's Father - TP1)*

The memory of seeing another child with a tracheostomy made Sam's mother hope that Sam "*never ever has to have a tracheostomy*"; the appearance of a tracheostomy, "*the look of them*", upset her. Tom's parents recalled their concerns about the appearance of a tracheostomy because they felt it would create a visible disability and were full of fear as this was the last thing they wanted for their child. Tom's father talked of this visible disability as being "*worse than having a mental issue*". Tom's mother considered that a tracheostomy for her son might cause feelings of pity from people who "*might see it [tracheostomy tube] and judge you*".

For two parents the thought of what their child would have to go through was scary. Matthew's mother talked of the thought of a tracheostomy operation being "*harsh*" for her baby:

> “*The thought of them putting something in my son’s neck. Didn’t like the thought of him having his neck cut open, or them to put this thing in. [….Silence…] Very scary definitely.*” *(Matthew’s Mother - TP1)*

Similar feelings were expressed by Jack’s mother who “*was not happy*”, and found it strange and hard to imagine her baby, who was “*so little*”, having a tracheostomy and hoped he would be “*alright without his trachy*”. She recalled being really upset about him having to have a tracheostomy because she thought “*maybe he won’t make it or something*”*.* Louise’s mother had been troubled and petrified for some time about her daughter having a tracheostomy as she explained:

> “*I had locked it away with the key and thrown it away, because I never ever wanted it [tracheostomy]. In my head it was the worst thing in the world that we could have ever done to Louise.*” *(Louise’s Mother - TP1)*

However, she knew that a tracheostomy one day was inevitable for Louise, as she explained:

> “*But well, as usual you move the goal posts don’t you? Like every special needs mum you put up with more and more and more and before you know it, you’re ready for a trachy and then you say, ‘When did that happen?’.*” *(Louise’s Mother - TP1)*

All of the parents came to the realisation that having a tracheostomy was their child’s only chance of survival**.** Seven parents recalled the tension of their child needing a tracheostomy and they battled with making tough and challenging decisions. Anna’s mother describes her fears when first discussing a tracheostomy with the consultant**:**

> “*He said to me, ‘Tracheostomy’. I said ‘What’s that?’. He said, ‘It was a tube that goes in the throat’. At first I said, ‘Under no circumstances unless it’s life or death do you touch her’. But he more or less told me, ‘She either gets it or she won’t survive’. So I thought, ‘God I am being selfish’. When he explained it a little bit more, what it involves and that she was not going to*

> *have it for life, it sounded a little bit better, just a little bit. It was very scary, unexpected you know, after three days of her being born. [I] was absolutely gutted [….silence….].*" *(Anna's Mother - TP1)*

Jack's mother told a similar story, depicting the stark picture painted by the consultant that Jack might not survive or "*grow to be a big boy*" if he did not have his tracheostomy; the operation would "*save his life"* and at this point she thought "*alright go ahead then*"*.* Tom's father recalled the time when he saw his son struggling to breathe and how he realised that Tom's survival depended on him having a tracheostomy:

> "*They tried NPA [airway] tube up his nose and he struggled it weren't helping, he was still de-sating. As parents the only thing that's there for him was a trachy. Yeah then when you're watching him in his incubator and he de-sats all the time, he was going blue and black. They were bagging him that side of it and you think that's not fair on him. If this simple task for us is to stop him going through that surely that's a better thing […. silence…..].*" *(Tom's Father - TP1)*

Tom's father considered a tracheostomy *to be* "*unfair on a child*" and he recalled his first feelings about a tracheostomy as, "*at first it was a big punch in the stomach*"*.* However, despite these feelings he recognised his responsibility, "*you got to cope with it, it needs to be done, he is still your child*"*.*

Rose's mother shared her emotions about her daughter needing a tracheostomy, saying how she "*broke down to be honest*, *I broke down in tears*", and explained how "*It was scary and our feelings, we were disheartened.*" She recalled questioning the doctors initially about the need for a tracheostomy and asking about it being permanent:

> "*Then they [doctors] told us about the tracheostomy. We were just shocked we even said, 'Why does she need it you told us she could breathe on her own'. That's when he told us, 'Her windpipe was too small and her tongue*

> *at the back is too big'. So when they said to us, 'She will need a tracheostomy', we asked, 'Was it permanent?'. He said, 'No it's not permanent it will only be temporary'. So when they said, 'A tracheostomy', I said, 'Is it difficult to look after a child with a tracheostomy?'. He said, 'No but it will take time for you to get used to it, 'cause obviously it's in her throat and it's visible'. I said to the doctor that 'I was not bothered if it was visible or not, will it help her breathe?'. He said, 'Yes', so I told him to do it, if it's going to help her breathe, do it, by all means do it […silence….].*" *(Rose's Mother -TP1)*

Two parents realised before the doctors that their child needed a tracheostomy. Louise's mother recalled, "*it was me who brought it up*". She wished for Louise to be free of invasive tubes, because she had enough of seeing her daughter suffer and "*could not stand to see her with all those tubes down her throat*". The realization for Louise's mother was that a tracheostomy was the best thing for both Louise and herself, as she explained:

> "*She was getting weaker and weaker and looking to be vented again. Whereas if she had a stable airway, we could do it from the stable airway, so that was my reason, that's why I wanted it. I had enough of seeing her with the tubes down her throat and her nose and I could not take it anymore. So that was why I started to push the trachy. We had a couple meetings about it and eventually they [doctors] agreed with me that it was the best course of action.*" *(Louise's Mother - TP1)*

Melody's mother expressed her feelings of anguish and how it was hard for her to see her daughter suffer during respiratory arrests. She also discussed how she became worried about the impact the respiratory arrests would have on her daughter. When she reflected back on the time before the tracheostomy, she said she wished that something could have been done sooner:

> ***"****To be honest as soon as she had it done I was wishing they had done it sooner. You don't know what could have happened during her respiratory*

> *arrests, you don't know if that could have damaged her. But as a mum you just don't want her to go through that. 'Cause even though she made it, it probably scared the hell out of her, people putting stuff on her face to get her breathing. She is probably thinking 'What the hell going on here?', it's not going to be nice and you can only imagine what it's like for them.*" *(Melody's Mother - TP1)*

Freya's mother remembered being told that Freya needed a tracheostomy and recalled that she "*felt horrible*" as it "*was the worst-case scenario*". In addition to facing the fact that their child might die because of respiratory difficulties, preparing for a tracheostomy posed other challenges for parents**.** Giving consent for their child's surgery and the consequences of the risks of surgery being clearly explained to them was very emotional, especially for Tom's and Anna's parents. Signing the consent form was a moment when emotions rose to the surface. Tom's father recalled the difficulty he had with the implications of what was at stake, when faced with the major risks of his son's surgery:

> "*He [consultant] took me off to a private room. He was going through the actual procedure, what the consequences could be as well. And on the list is death and the thing is part of what could happen, airway compromise and all these things. So as parents you're told this might be more secure but you don't really take it into consideration, those consequences. You sign that form for [the consultant] to go away and cut your son's throat (Father gets emotional and cries, mother comforts him) […… silence…..].*" *(Tom's Father - TP1)*

Anna's mother faced the risks of surgery when signing the consent form with the consultant and described them as "s*cary you know*", and talked of how emotional it had been for her when the doctor had explained the implications of surgery; "*I had a little bit of a cry cause he mentioned the death word*".

Furthermore, facing the day of surgery was an emotional time for some parents and they recalled crying, feelings of distress and sadness. Like most parents Freya's mother was upset and explained: "*It wasn't a very nice day*, *when she went [to theatre] we were a little upset, we just waited basically in her room*"*.* Anna's mother also recalled her feelings of that day; "*I did nothing but cry when they took her*"*.* Rose's mother had seen her daughter go through three operations and she talked of how she "*felt sorry for Rose having to go through another operation 'cos she already gone through three*"*.* Louise's mother talked of the roller-coaster of emotions she experienced and feeling tested to the limit because of the lack of control when Louise's operation did not take place as planned:

> "*She was on the emergency list. I told myself I heard about this emergency list, it's not going happen today [….laugh…]. So I was fine and then someone said, 'She's going down in a minute''. I just burst into tears, I was like, 'Oh no I am not prepared.' I was like a wreck. The staff were saying, 'You're always so strong'. I said, 'Oh no I am not psyched up'. Next minute the nurse popped in and said, 'Sorry, she's not going down yet'. God, the mental torment, it was awful, I was shaking like a leaf.*" *(Louise's Mother - TP1)*

The operation went ahead the next day, sooner than Louise's mother had anticipated due to Louise struggling to breathe again and because "*it was possible that we needed to vent her again, I just could not bear for it*"*.* She recalled how the specialist physiotherapist intervened in getting Louise to theatre:

> "*The physio came. He said, 'She needs to go'. 'I know', I said. He said, 'Leave it with me'. He came back and said, 'I had just spoken to the consultant anaesthetist and told him, she has to go now'. Within 20 minutes we were off. He [physio] said, 'We can't risk doing that to her [going on a ventilator], it's not fair'. Before I knew it, I was in the theatre room giving her a kiss and saying my goodbyes a bit quickly but probably the best." (Louise's Mother - TP1)*

Reacting to seeing their child for the first time following surgery drew an emotional response from the parents as they came to terms with seeing their child for the first time with a tracheostomy. Jack’s mother reacted strongly to her son’s tracheostomy and said, “*I was quite shocked like when I saw him after the operation*”*.* Rose’s mother remembered, “*I was shocked; at first cause it did look a bit hideous”.* The following quotations convey a sense of how Louise’s mother and sister felt following Louise having her tracheostomy. Louise’s mother emphasised how she was emotionally “*devastated*” and the struggle she faced in accepting and seeing her daughter after surgery:

> “*I could not look at her without crying, even though I knew it was the right thing to do. It was just like there is that thing that I promised I would not do to her, or I would make sure we’d never go down that road. On that first day I think I just cried all the time, I just cried and cried and cried.*” *(Louise’s Mother -TP1)*

Louise’s mother then talked about how Louise’s sister (Courtney) reacted to seeing Louise for the first time with a tracheostomy, which she recalled as alarming and upsetting, and how she needed to support Courtney. Courtney described the tracheostomy as, “*it’s horrible horrible to look at*”, and saying, “*I hate it can we please go and buy her some scarves*”*.* Furthermore, Louise’s mother remembers her feelings about Louise’s own reaction to her tracheostomy, explaining that Louise “*was having lots of these crying episodes after her trachy*,” and recalled someone saying, “*Louise is probably fed up*”, and how she concluded that this was probably true after all that she had been through.

Conclusion to, ‘We had no choice’

Parents told stories that reflected the challenges they faced when their child’s life was at stake because of their breathing difficulties. The need for a tracheostomy resulted in them experiencing shock and upset. A strong emotional thread running through these stories was linked to the parents’ difficulties in making decisions about a tracheostomy. This led parents to experience distress because a tracheostomy was not what they wanted for their child but they recognised that they needed it to save their child’s life; they had no choice but to ‘go with it’.

Sub-story: Learning to reframe

The parent's lives took a different turn when their child had a tracheostomy: a turn which they did not imagine would happen. In three families the parents were new mothers and fathers, whilst the remaining six families had one or more children already. Each parent had their own way of facing the challenges of their child needing a tracheostomy. However, the initial stages of learning to care for their child's tracheostomy were fairly pressurised, intense and testing. Parents talked of how they faced going home and how the impact of other people's reactions to their child's tracheostomy affected them and their child.

Parents were anxious when learning to care and becoming competent at managing their child's tracheostomy. Six parents described their feelings when learning to change their child's tracheostomy tube. Sam's mother found facing the first tube change incredibly hard as she recalled:

> "*I kept trying to put my first tube change off. I remember [dad] doing his first changes and I didn't faint but remember feeling a bit faint. I thought I am not going to be able to do this and I keep saying, I think I said to yourself, 'I am not going to be able to do it. I can't I know for a fact that I won't be able to do it'. But then I knew I had to do it [said boldly].*" *(Sam's Mother - TP1)*

Sam's father thought doing his first tube change was a "*big deal*" and he recalled how he felt "*quite emotional*" after the tube change had happened as it had been "*something new*".

Jack's mother was concerned about changing his tracheostomy tube because "*his life depends on it*" and she recalled how "*nerve wracking*" this was, and how:

> "*It does not get any easier. It's just something you keep thinking about and then when you have done it, you're more relaxed until two weeks before you do it again. Because he struggles with you, when you are doing it sometimes, it's quite scary. If he is calm when you are doing it it's much better. I don't know, maybe with time he will become calmer, sometimes he*

> *struggles and cries and it frustrates you more seeing him like that so […..silence…].*" *(Jack's Mother - TP1)*

Anna's father recalled his feelings about the first time he did a tube change on his daughter and remembered that it made him "*cringe and I feel it's horrible*". He went on to describe that he still feels:

> "*Anxious, apprehension, anticipation, my stomach turns you know. But I know, I know, when I come to do it, I have got to do it. I got to stay calm and do it and panic after. 'Cause I know, I got to do it right and do it right for her.*" *(Anna's Father - TP1)*

He talked about how he feels guilty; "*I feel guilty, cause I wonder what they are thinking*", because he was concerned about Anna's reaction to the tube change as well as his own. Anna's mother remembered carrying out Anna's tube change as an emotional experience of panic, anxiety and then ultimately feeling happy because it was over:

> "*Was dead anxious, you did not know what to expect. I was thinking what if it doesn't go in, but it does doesn't it, and you do do it. It just happens doesn't it? But afterwards, after I had done the trachy change, that's when I panicked. I felt me body you know tears in my eyes and stuff cause in a way, I was happy that I had done it. Because I was so anxious before and it was very emotional, yeah. And it would be like that for any parent wouldn't it? But yeah it is a scary thing.*" *(Anna's Mother - TP1)*

Once the parents became clinically competent to care for their child's tracheostomy, planning for home caused them to experience mixed emotions. The prospect of going home caused the parents concern and worry: their main concern was sustaining their child's tracheostomy care at home. However, the parents were also looking forward to going home. In general, the mothers found it natural to take the lead parenting role at home and this included the clinical care required for their child. As Anna's mother stated, "*Well I know I am in charge [we all laugh*]." This impacted on parents in different ways and some mothers gave up their jobs to care for their child. The everyday practicalities of having a child with a tracheostomy were life-changing for Louise's mother, who describes how the responsibility of the caring role fell upon her, "s*o it's down to me, it is my life that's changed and not really his so much, it's a big pressure*"*.* Despite Louise's father taking on some of the caring role, conflict occurred between them over clinical decisions, as Louise's mother explained:

> "*I've got work on a Wednesday. So I can get a night's sleep [Dad] looks after her. I came in to see Louise this morning and he's cranked her oxygen up but I felt her chest and she just sounds really bubbly. So it's not oxygen she needs, it's some good coughs, it's nebs she needs to break it down, it's physio to shift it. Its maybe bits of bagging to make her cough you know. But he's just, been up and down with her all night thinking, he can just throw oxygen at her, that's all he does. But I'm always with her, he works the most, you know he, he's not the expert.*" *(Louise's Mother - TP2)*

Most of the fathers worked full time and outside of the house and as a result had limited time in the caring role. Some fathers were described as less confident and experienced in caring for their child's tracheostomy than mothers. Freya's father worked away for months at a time and this impacted on his confidence to undertake some of Freya's care, which affected both him and Freya's mother, who explained:

> "*He's still not comfortable with the trachy and doing that stuff but he's not here all the time. So, but he does help but we end up arguing [...Laugh…]. I do prefer it when he's not here from that point of view. We have a better routine but it is what it is.*" *(Freya's Mother - TP3)*

Rose's mother recalled a phone call from her husband when she was working her last shift. "*I gets a phone call off [dad], he said, 'You will have to come home now' ",* as an emergency had occurred at home; Rose had "*literally undone these tapes, she must have pulled it with such force".* She recalled that *"by the time I'd come back William [sibling] had got my mum round to tie the tapes*"*.*

However, for one father the pressure of going to work impacted on his home life and his ability to help care for his son. Meeting Sam's day-to-day care demands was difficult for the whole family so Sam's father took a career break, as he explains:

> "*I needed to take some time off work and so I was in a position where I was able to request a career break. Just to be home you know to make things a bit easier, which it has. We were feeling the pressure, I was, trying to get a balance at work but it was getting to the point where, it was just failing. Work was failing; I think work was fair. But it was coming to the point where I had to carry Sam, we've got no lifts, we've got no hoist. It was getting to a point where I would have to come home at lunch. I was having to nip out when he had appointments, so it was a lot of time lost really in work and something had to give. Obviously it couldn't be home, so it had to be work. They've been very accommodating; they've given me as much time as I need off. Which is good, it's good for us.*" *(Sam's Father - TP3)*

Despite parents looking forward to taking their child home from hospital, this time was also associated with anxiety about how they would manage and cope with their child's tracheostomy care. Tom's mother remembers her mixed feelings of leaving the security of the hospital behind as she faced taking her child home:

> "*Over the moon, a little bit apprehensive, that we're not going to have that 24 hour support behind us with the nurses and the doctors and everything, so scared as well.*" *(Tom's Mother - TP1)*

This mother recalled feeling "*full of nerves*" on the drive home from the specialist hospital and thinking, "*oh my god we are going home*"*.* Matthew's mother's biggest fear about going home was the possibility of having to do life support on her son, and not really being prepared for it, but knowing "*you've just got to get on with it and do it*"*.* She describes being "*scared of home*" and being:

> "*Afraid of the night time. Scared I won't wake up and hear him if he is in trouble or something like that. Scared of the possible chance that I would*

> *have to resuscitate him myself. I don't want that to happen. It's so frightening and scary it freaks me out a bit you know. To be honest I am not happy about having to do it but it's what you got to do. [….silence…]*" *(Matthew's Mother - TP1)*

Finding her "*confidence*" was low because of spending so much time in hospital, Louise's mother acknowledged "*worrying*" that her ability to care for Louise at home was lacking. However, once at home, she said "*we were fine*", but at the same time she acknowledged being apprehensive about looking after Louise's tracheostomy at home because she had not looked after an "*an artificial airway*" before. Anna's mother described being in hospital as "*safe*", as if she were "*in a blanket*", but accepted the need to confront her fears of going home, and explained *"I am going to venture out. Take her home even for the morning and bring her back*". Jack's mother's worry about facing home was going out with Jack, and she explained that she had "*been thinking about it and like I don't think you can go into some public places*"*.* She recalled her worries about Jack getting an infection and said, "*I feel maybe he might catch something*"*.* She was concerned her fears might "*deprive*" the family from going out and was concerned about "*being over protective*".

Parents also recalled the times when they had to deal with other peoples' reactions to their child's tracheostomy. Central to parents' experiences were stories about the lack of understanding from people about their child's tracheostomy. Dealing with these issues had the capacity to directly affect the parents, causing them added pressures. Negativity from other people towards their child's tracheostomy was described as an additional and unfair obstacle for them to face, as what they really needed was understanding, support and compassion. Tom's father recalled visiting home and a friend approaching him about his son's illness:

> "*Yeah I was back home at the weekend and friend of [mum's] came to me and said, 'Sorry to hear about your boy, I feel sorry for you having to go through all that. Feel sorry for you having to do those changes and things'. It's like what you sorry for, you not been in that situation, so how do you*

> *know how it feels? Why not say congratulations first as we had a child.*" *(Tom's Father - TP1)*

Tom's father went on to explain that "*rather than just assuming it must be bad. What we needed was empathy not sympathy*"*.* Jack's mother recalled how sudden silences from people impacted on her feelings, as she explained:

> "*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 cause they feel like it's too much, so it goes silent. People who have been pregnant too have had their babies, they go to the school, you feel terrible like this is terrible. But that's how sometimes it is [……silence………..] you just have to go with it and manage it." (Jack's Mother - TP1)*

In addition, parents discussed their concerns about people's prejudices towards their child's tracheostomy. Anna's mother describes her feelings, "*you know people stare and these people know nothing about it*"*.* She went on to explain how she considered not taking Anna out:

> "*I never heard of it. I seen a trachy but I did not know what it was, but yeah you do think what are other people thinking? Wonder why that baby's got that? People don't know do they? You know, at first I was thinking I won't take her out much. But no, she's my daughter, I love her, she is beautiful and it doesn't matter, it's there to save her life.*" *(Anna's Mother -TP1)*

Similar feelings were expressed by Rose's parents about people staring at Rose, although Rose's mother admitted to staring at other children who have special needs saying, "*I do it myself [laugh], arrr what's wrong with him?".* Rose's father's perspective was pragmatic, "*if they stare [I] tell them to go and do one, she is ours that's it end of*". Rose's mother accepted that "*every baby is different and obviously Rose, Rose is one of them special babies*". Other parents had fears relating to the social impact of a tracheostomy and for Sam's father these related to using the suction machine in public and "*how people would perceive it*", and Sam "*losing his voice*"*.*

Distress was experienced by the parents as a result of people's negative attitudes towards their child's tracheostomy. Melody's mother was confronted by a member of the public in the supermarket, when she was suctioning Melody's tracheostomy, and she recalled the reaction she experienced from this person, as she explained:

> "*I've had people saying, 'Do you mind not suctioning her?', and I have just turned around and said, 'Well do you prefer a dead baby next to you instead?' They said, 'How dare you do that in front of me?'. When all it is, is like wiping your child's nose. We were actually in the queue in the supermarket, all we were doing was buying pistachio nuts and we had that said to us. She had a really nasty cold and they said, 'How dare you do that it's disgusting, why do you do that in front of people?'. You just feel like, why you would do that to a tiny baby? There is obviously something wrong and they don't know how hard they'd had to literally fight to even be alive, so it just annoys me more than anything, and I feel that they are too rude*. *(Melody's Mother - TP2)*

Melody's mother found it difficult to cope with the reactions of others; "*it affected me quite bad*", recalling that she needed "*anti-depressant tablets*"*.* She talked about her anger towards Melody's father, saying "*I was getting quite angry with [father] all the time*", and how in the end she "*just didn't want to upset anyone*", and how it was hard when they went out, and deal with people's reactions to "*take it*"*.*

Rose's mother recalled that "*when we first brought her home it was, frustrating*". She recalled that "*people used to stare when you started giving her suction*"*.* However, she talked of how outraged Rose's brother is and how he confronts other people by saying "*What are you looking at?*", and how people would say, "*Oh we're so sorry*"*.* Rose's mother's reaction was to be glad her daughter has a tracheostomy rather than the alternative of not being alive. She explained, "*What's there to be sorry about? She's here, she's alive*"*.*

Two parents talked of how their family could show a lack of understanding towards their child because of their tracheostomy. Tom's father recalled his irritation because family members primarily focused on Tom. "*The only thing that gets to me is people always say, 'How is Tom?' "*, and he thought they should also be interested in Tom's sister; "*they don't ask how Sarah is*". However, he went on to explain that because Tom has a tracheostomy this should not make any difference to the family unit:

> "*We got two children, Sarah's part of it as well. Just because he has got this [tracheostomy] doesn't make him any different.*" *(Tom's Father - TP2)*

Sam's father recalled his feelings about a family misunderstanding and the danger of glitter to Sam's tracheostomy:

> "*Our niece had this dress, it was a lovely little dress but the glitter, it was just shedding glitter and [mum's] other sister was like 'She [niece] be fine, she can go by Sam.*" *(Sam's Father - TP2)*

Sam's mother explained that "*there's no way with a dress like that*" that the niece should be close to Sam because of the danger that glitter could go "*down his trachy*" and Sam's father was also concerned about "*that sort of lack of understanding*"*.*

Parents faced frustrations with getting the right care for their child at home. Parents felt that the care offered was unacceptable and this challenged parents when seeking the right care for their child. Louise's mother recalled the difficulties even with direct payments in "*finding that tracheostomy trained person*" to give the appropriate care to her daughter. Looking back over twelve months she talked of the continued strain to get tracheostomy trained carers:

> **"***I got a small window of about 3 months of good care. However, it came crashing down they [the carers] all got pregnant. So I had community matron ringing round finding agencies, she found one, I won't name them but they promised me trachy trained carers, I thought wow! But their version of trachy trained is death by PowerPoint. I arranged a full day's training*

> *course for my carers to sign them off on trachy CPR [Resuscitation] and to cater around Louise's needs. It was expensive because I wanted a full day, I actually emailed the agency and said 'Listen, this course, I really need your girls to come on this'. They said, 'They don't need to go on a course they are fully trachy trained'. I said, 'I don't agree, they are not trachy trained, they have never changed a trachy, they don't know situations if she went into spasm, you know if you could not get it in [tube] or try the Seldinger technique'. They said, 'Oh no they don't do that [Seldinger technique]'. So I am like, 'Right, I don't agree'. So anyway all my girls went off on mat leave, the course got cancelled, I have got one carer. I can't leave her though it's hard to trust.*" *(Louise's Mother - TP3)*

Jack's mother had issues with her care package because it restricted her going out, as she explained:

> "*With the care package you can't leave the house. I felt it should give you a break, it should let you go out […silence…..]. As a parent, do some shopping or even just for fresh air but you still have to be in […silence…..] as well." (Jack's Mother - TP2)*

Conclusion to 'Learning to reframe'

Parents told stories that revealed how they learnt to care for their child's tracheostomy and the negative reactions from some people towards their child's tracheostomy. In particular, parents expressed their emotional feelings about changing their child's tracheostomy tube. Reactions from people to their child's tracheostomy were upsetting for parents. However, they learnt from experience to hold their own in such situations by facing the situation head on. Some of the parents discussed the frustration of not getting the right care for their child, for instance not finding the right carer with tracheostomy skills. These added to the overall stresses that the parents continued to experience.

Core story: ‘Holding their own; coming out the other side’

Introduction to core story: ‘Holding their own; coming out the other side’

The second overarching core story told by parents was about less stressful times, and the stories had a lighter tone and feeling about them. These stories were about times when they had left the stress, shock and upset behind them and had accepted a future as parents whose child had survived a life-threatening experience and had a tracheostomy. Coming out the other side brought the parents into times of relief, happiness and finding balance within their lives. Once parents saw the positive change a tracheostomy brought to their child’s breathing issues, they allowed themselves to hope, and this brought them comfort and relief.

Parents talked of how they were a “*good team*”, supporting each other and finding the right balance between them as parents. They also talked of how reassurance from friends and family was important to them. Within these stories parents reflected on the past and thought of their future. These stories were mainly experienced after the parents came home. However, some parents saw an immediate change to their child’s breathing after the tracheostomy was inserted and this change had a positive impact on these parents. This core story is composed of three sub-stories: ‘We see a difference’; ‘Living in the everyday’; and ‘Looking back, looking forward’’. In the following sections, these sub-stories are explored in more detail.

Sub-story: ‘We see a difference’

The most comforting period of time for parents was when their child’s breathing became stable after they had a tracheostomy inserted. This brought parents relief because their child was alive, and the parents recognised just what had been at stake for their child. Once parents could see the change in their child’s breathing issues due to a tracheostomy they told positive stories of how this had transformed their situation. Six parents expressed relief and comfort because a tracheostomy had allowed their child to survive. Sam’s father recalled soon after the operation, “*he is our baby it’s a good thing and it’s worked, it’s worked for him*”. Two parents recalled how they felt instant relief after seeing their child following surgery. Freya’s mother remembered the difference she saw in her daughter following her tracheostomy operation; “*she was* *just settled, she went to sleep by herself which was the first time"*. She went on to talk about her feelings once she realised the changes she saw in her daughter were because of her tracheostomy:

> "*It was alright, then you know we've all got over it, it's just normal now […silence….]. It was a relief because of how much she was struggling before. Because she obviously would never have done that before like ever […laugh......] she was a very naughty baby [….. laugh.........] she is different now.*" *(Freya's Mother - TP1)*

Tom's mother tells of a similar experience, as she remembered her relief following his operation; "*he came back from theatre, I cried with relief*". She remembered how Tom looked "*so much happier*" and how "*just thinking about it now you just feel that relief again*". She talked of how astounded she was that the tracheostomy had made such a difference to Tom, "*that little bit of plastic makes that much difference to our little boy's life - amazing*"*.* Finally relaxing following his son's tracheostomy and enjoying being a parent, Tom's father recalled "*seeing him happy. We just sat back enjoying him and saying 'oh what bother?'. Nothing to worry about.*"

Five parents talked of how a tracheostomy had been the right decision for their child as it allowed their child to flourish, and how it was the "*best thing*" as it had helped their child to "*survive*". Tom's mother recalled, "Y*es we're really really grateful for it [tracheostomy]. Absolutely. He's turned into a proper little boy now, he's made it*"*.* Melody's mother shared her feelings of how a tracheostomy was a "*good decision*" that had helped her daughter to "*thrive*" and that even though she is "*still very small, we know what her issues are now [with a diagnosis] and it's helped [the tracheostomy] to overcome them*"*.*

Jack's mother appreciated what had been done to keep her son alive:

> "*I am grateful. 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 - TP3)*

Louise’s mother explained why a tracheostomy had changed Louise’s life, especially when she becomes ill, as she explained:

> “*Now she’s got the trachy, when she got poorly it helps her. She got bronchitis and she needed CPAP [breathing device]. Well we know she just doesn’t tolerate the CPAP masks but it was great, it wasn’t an issue cause it was just clip it on the trachy. I believe that if she didn’t have that trachy, she wouldn’t have tolerated that, she wouldn’t have got any better she would have deteriorated […silence…].*” *(Louise’s Mother - TP2)*

Louise’s mother continued to explain the difference the tracheostomy has made and explained it “*had been the best thing*” in keeping Louise safe, as Louise can go “*downhill really quickly*”, but with the tracheostomy life is “*safer, easier as well, it’s really good, the trachy*”*.* Matthew’s mother talked about how a tracheostomy had given her son a chance to live and grow, allowing further surgery in the future, as she explains:

> “*He’s been able to be like a normal baby. We just had to wait till he was bigger. So that he was stronger and bigger to deal with the operation to repair his airway. Cause he would have not been [big enough] when he was first born, so it’s [tracheostomy] saved his life [….silence……].*” *(Matthew’s Mother - TP1)*

Rose’s mother felt able to advise other mothers because of the positive “*life changing*” changes to Rose’s life*:*

> *“I’ve had a few mums-to-be actually saying to me, ‘If my child was not able to breathe or anything, what do you reckon?’. I said, ‘Go for the tracheostomy,’ it’s the best thing. You’ve got to take equipment with you but what’s more, what’s more important to your baby? It’s been a life saver, it’s helped Rose.” (Rose’s Mother - TP3)*

Many parents talked of their relief and comfort from the positive impact that the tracheostomy had on their child’s life. In addition to this relief, the parents told stories of how this then led them to reconsider their own dark initial feelings about a tracheostomy. Sam’s mother remembered her initial feelings about Sam needing a tracheostomy; “*I thought I would be terrible about this trachy but I wasn’t*”. When the tracheostomy did not turn out to be a bad thing, parents became more relaxed and comfortable with the decision because they believed the right thing had been done to save their child’s life.

Sam’s father recalled how different his feelings were once he had seen Sam following his surgery:

> “*I had sort of had this vision of us going into Recovery, obviously you going to be upset as he just had major surgery. I did have a vision of me falling to the floor and we thought it was the end of the world and it wasn’t! We went in and he was crying, that was yeah that was really strange. Yeah a completely different baby and even the tracheostomy itself, the tube and the Swedish nose that was always a fear. Cause we saw a little baby didn’t we and it was quite pronounced but whether it’s because he is our baby you don’t even notice it.*” *(Sam’s Father – TP1)*

Putting off Sam’s tracheostomy now made his father feel guilty because “*we left it so long*”*.* He recalled how it was hard to come to terms with Sam’s breathing issues before the operation:

> “*We weren’t admitting it, his breathing, we thought it was fine. When you look back at the videos it’s anything but normal or fine, but it wasn’t right was it?*” *(Sam’s Father – TP2)*

Jack’s mother expresses how grateful she was, because the consultant had “*saved*” Jack. She recalled how grateful she was that “*he saw the scar [in his airway] to save him, maybe we would not have him here like right now”*. Tom’s parents recalled how what seemed “*so huge at the start*” now seemed like a “*dummy but in a different place and we are grateful for it*”*.* Tom’s mother explained how things that felt “*awful*” to begin with are now different, and how she feels “*quite sort of proud of me that I can do this for my child*”*.* What mattered to Tom’s parents was that “*he is Tom regardless of anything, he is Tom and we love him, he is alive*”, and he has “*turned into a proper little boy now. He’s not a baby any more*”*.*

Other parents talked of how life-changing a tracheostomy had been for them and their child, as Rose's mother explained:

> "*It's been life-changing for Rose. It has actually brought life into perspective do you know what I mean? I just get on with it because well, she's here. I've overcome them emotions now […silence…]. So what she's got a trachy, she's here, she's alive, she's kicking [……….laugh…].*" *(Rose's Mother - TP2)*

Thinking back to how Courtney (Louise's sister) had struggled initially with her sister's tracheostomy, Louise's mother explained that:

> "*Courtney is fine with it now, she's doing really, really well, 'coz you know she wanted her to wear scarves, didn't she? But no, she doesn't bother anymore. So [Courtney's] feeling a lot more relaxed about it now .You can tell, she approaches her more. She always kisses and cuddles her and is always telling her she loves her. So she seems much, much better.*" *(Louise's Mother – TP2)*

Conclusion to, 'We see a difference'

Parents told stories about less pressured times when they were less upset and anxious about their child's tracheostomy and able to 'hold their own' because their child had flourished following the operation for a tracheostomy. Parents accepted and were thankful for the tracheostomy because it brought with it a sense of relief and comfort.

Sub-story: 'Living in the everyday'

'Living in the everyday' tells of how the parents over a period of time became settled. As a result, they discovered the importance of working together as a team, getting to know their child's needs, finding reassurance and comfort as well as receiving support through other people. Parents told stories of how they established routines once they had been at home for a while. They talked about being more adept at doing the clinical aspects of their child's care. These routines and increasing competence freed up time for parents to plan normal routines for their child, and for them as parents to look after themselves.

Entering into calmer times brought them ease and comfort. For instance, Tom's mother explained her feelings about their routine at home; "*I think we are doing a pretty good job actually, we settled into a nice routine*". For Freya's mother, being at home became easier than remaining in the hospital as she recalled, "*I mean it is hard work but once we settled at home and in our routine it has been a lot easier than being in hospital*"*.* Parents recognised how "*important*" routines were, and talked about the significance of this. The parents of Sam, Rose, Tom, Melody and Jack all talked about their routines at home. Sam's father recalled how he now manages his son's tracheostomy care with confidence:

> "*It's old hat now the trachy it's nothing […. laugh ……….]. We are in a fabulous routine, what does our routine involve [mum]? [……… laugh……………] where I do everything [… laugh……]. His neck is not sore his site [stoma] fine, I am fine with it, his site is perfect, touch wood, no leakage or anything like that no discharge you know, it's healed well, no redness or anything like that. We do his tapes and dressing. It's a five minute job, it's a bit fiddly but so much better as you become used to it don't you? [….silence………].*" *(Sam's Father - TP2)*

Establishing a routine at night time was important to Rose's mother so that Rose manages to "*get a good sleep*"*.* She reflected on how happy she was that this was going well and described how this had impacted on the rest of the family:

> "*She sleeps from nine o'clock to between six and seven in the morning. Waking up twice during the night obviously with a little cough but I mean that's it but she's asleep. We get her in bed by nine, William's [brother] in bed by half nine, so we're back to our little family routine – it's brilliant, absolutely brilliant.*" *(Rose's Mother -TP2)*

Tom's parents recognised the importance of parents working together, and explained "*We don't really feel that we needed a care package or anything do we?*" *(Tom's* *mother)*, because they felt that they could manage Tom’s day-to-day care together, as Tom’s father described:

> “*I get up with him in the morning while [mother] gets ready and then, she takes over [mother], I can get ready. I go off to work and come home and I play with him till like bath time, tapes time and we put him to bed. So it’s all about getting in the routine and working together.*” *(Tom’s Father - TP2)*

Keeping each other refreshed was a significant factor that Tom’s father considered to be important, as he explains:

> “*It’s giving each other time to have that rest as well at the weekends. On Saturday [mum] will have lie in and on Sunday I will, or other way round just to recharge your batteries. You know we are in the same house, if anything goes wrong we’ve got each other there. It’s just keeping yourself fit and healthy and awake as possible. As it would be impossible to do if you are half asleep.*” *(Tom’s Father - TP2)*

Melody’s and Jack’s mothers talked of their routine when changing their child’s tracheostomy tube and tapes at home. Melody’s mother recalled their regular daily routine as being more manageable:

> “*We just liked doing everything ourselves. 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 and if it’s her dad doing it, he gets it in a lot quicker than me. She doesn’t notice it’s in and out. I do it a bit slower, as I do it with her breathing. Since we’ve been home it’s not really been too bad. She always copes well, she can a bit grumpy afterwards, but she always has done.*” *(Melody’s Mother - TP3)*

An important factor for Jack’s mother was that her son was relaxed when changing his tapes as when “*he’s settled you’re not as scared*”. This meant that she preferred to do his tracheostomy tapes herself as “*he is more relaxed than someone holding him*” when doing the tapes to secure his tracheostomy tube in place. She also talked about how experience of changing his tubes has significantly changed over time and she is now "*happy*" and "*confident*" even though he is "*still a rascal*" and "*wriggles a lot*", *a*s she now knows "*what to do with him*"*.*

Other parents talked of how the tracheostomy care time had become more relaxed for their child, as Tom's father explained:

> "*The tracheostomy doesn't bother him in the slightest. It's not bothering him when doing a trachy change, it's not bothering him doing his tapes; nothing fazes him he's so laid back. He is content he's had a little spell of pulling on it to get our attention. And now he just grinds his teeth, which is even more annoying […laugh….].*" *(Tom's Father - TP3)*

Everyday life for Rose's mother was "*getting better*" and more like a "*basic habit now*" *as* she was more organised:

> "*Make sure you got the spare trachy bag, make sure you've got the oxygen, make sure you've got the Ambu bags.*" *(Rose's mother - TP2)*

Two families told stories about how their other children liked to be part of the tracheostomy routine. Freya's mother talked of how Darcy (Freya's sister) likes to get involved in the family routine and tells her school friends that her sister has a tracheostomy:

> "*Her sister wants to be a little helper but she is a nightmare […laugh….] she wants to do everything. 'Can I suction her? Can I do this? And can I do that?' So every time she does her tapes she is perched on the table passing us things (laugh) it has been quite funny […laugh…]. Yeah so she told everyone in school about it, she took pictures in and told everyone about her sister's magic tube, her breathing tuber as she calls it.*" *(Freya's mother - TP2)*

Tom's parents told a similar story and talk about how "*amazing*" Sarah (Tom's sister) is, and how she helps with her brother by "*talk[ing] away to him*" to help him calm when he needs his tracheostomy attending to:

> "*Sarah helps, she got her own doll she now lies or sits next to us on the chair while we are doing it [his cares]. So he absolutely adores Sarah. So he just watches her and lets you do whatever you need to get on with.*" *(Tom's Father - TP2)*

Settling into the everyday routine for three parents meant providing their child with a normal childhood routine by getting them to mix with other children and socialise like other children. Tom's mother described how it was important for Tom to be "*getting out and about at a baby group*", and explained:

> "*We go to a sign group as well so were trying to learn sign. So were trying to do the everyday-to-day stuff. He enjoys just sort of being around other kids and watches them run around.*" *(Tom's Mother - TP3)*

Melody's mother talked about how important it was for Melody "*to get into playgroups*" because "*she has so much fun*". She went on to describe how Melody loves "*painting and playing with [friend] her bestest buddy!*". She also recalled a field trip where she did not accompany Melody who "*actually got to go like a normal child would on her school trip*". Freya's mother talked of similar friendship experiences and social routines for Freya.

> "*Well she got a little friend and he's like three times the size of her but she loves him [….laugh…] so we do meet up with them quite often. She likes going and playing with him and I am taking her to a baby signing class as well in a couple of weeks.*" *(Freya's mother - TP2)*

Support networks were an important source of comfort and help to the parents. Parents believed that social media was an important source of reassurance and empathy. Three parents described maintaining a link with other parents via social media whose children had a tracheostomy; this link with other parents was invaluable to them. Tom's parents explained how supportive this was in providing them with advice as "*you get really useful little hints and tips*" that can be comforting. He went on and explained:

> "*There is a group [social media site] support group who are brilliant just any little question, you got somebody who knows the answer to it. You can go on it and say I am so fed up or something and everyone's like 'Oh yes, I know exactly how you feel'. So even though you haven't actually met any of these people, it's still good to be in touch with them because a lot of their kids have a trachy. There always someone who's got an answer for you or that little bit of, well just support or comfort.*" *(Tom's Father - TP2)*

Both of Tom's parents continued to talk about how helpful they had found this support and would "*advise anybody who gets a baby with a trachy, just to go on them sort of pages*" *(Tom's father).* Tom's mother explained how she has now "*helped people as well, helped them get hold of things and what you are entitled to*"*.*

Melody's mother described the social media site as a "*normal group of friends*" who "*know what you're going through*" and who provide invaluable support to her and Melody:

> "*I've met a lot of good friends through [social media] and they are there for me and Melody so we kind of know what everyone's been through. It's good that if you can get a number or code to order, you'll find someone who knows the number or code […silence….], so it does work and with added support when you are fed up.*" *(Melody's Mother - TP3)*

Liaising through social media with other people who have a tracheostomy allowed Louise's mother to gain an insight into how having a tracheostomy feels for a person, because she was concerned about Louise being upset due to her tracheostomy, as she explained:

> "*I have asked the [social media site] a few times about, about pain, about things, I always worry, because she went through a phase of crying again. It turned out it was stomach pains [….laugh…silence…] but I worried that it was the trachy. There are a few people on there that have got trachies that are able bodied, who can tell you, 'Oh gosh no, don't feel a thing'.* " *(Louise's Mother - TP2)*

Support from other sources, especially the community nurse, was also important to parents. Tom's mother described how "*the community nurse is good*" as she "*is always asking us if we need anything*". Freya's mother also praised the community nurses, saying "*they are always there supporting us*". Melody's mother talked of the assistance and back-up from her community team:

> "*They can't do enough for you, they always make sure they ring to see if you need more equipment. They went out of their way to get a quieter suction machine because the one we had was very loud. They treat Melody like a princess. They're always in fussing over her and they actually ask how you are. And they sit for a good while, and actually see how you are, have a little play with her, have a cup of tea. So you've got company as well.*" *(Melody's Mother - TP2)*

Freya's mother also talked about the support she receives from her family. She described her own mother as "*good help to me*". She continued to explain how Freya's care can be shared within the family and stated "*we do have family fighting over who is going to come and help and do tapes*". However, at times it was overwhelming having "*that many people wanting to help*".

Conclusion to, 'Living in the everyday'

Parents developed into their chosen routine and were happy with the progress that they and their child had made since their tracheostomy had been inserted. This allowed them to become more confident and comfortable in their child's care. Support through a social media forum for some parents was important and they described this as invaluable. Parents also talked about the value of support from the community professionals and family members.

Sub-story: 'Looking back, looking forward'

The most reflective stories for the parents came when they took the time to think about the past as well as discuss their hopes for the future. There was a sense in their stories that their lives were filled with contentment and hope as their child had survived and the parents had regained order in their lives. Following their shocking experiences around the time of diagnosis, parents who were content believed that their child had a future. Their experiences had made them stronger and helped them to face their future as a family. The initial shock of a tracheostomy was reflected upon by seven parents who talked about their feelings twelve months on. Sam's father reflected on the past as he offered advice to other parents who faced the same experience:

> "*And really the advice I suppose, to any individual parents who would be presented with the same situation, would be, just to go with it, go with the trachy, it won't be a bad decision, an emotive one but not a bad one.*" *(Sam's father - TP3)*

Looking back, Melody's mother described how she "*fully trusted*" the consultant and how he "*saved [Melody]*". Her initial emotions about the tracheostomy were that she was "*prepared for it [tracheostomy]"* and "*knew it was going to happen*", and said, "*You've just got to laugh or you'll cry, but we won't know what to do without it now*"*.*

Freya's mother talked about how they have "*learnt to see*" the tracheostomy as "*just another thing*" and "*are so grateful it's been a life saver for Freya*"*.* She explained that her "*cheeky"* daughter is "*doing really really well*" and that she "*truly believes*" that this is "*down to the tracheostomy*"*.* As for Freya, she is now "*a little monkey, never keeps still, she is a right live wire*"*.* Jack's mother was also "*so grateful*" to the consultant as she believed "*the tracheostomy helped him [Jack] live*", and thinking back "*we did not know*" that Jack was not getting "*enough oxygen in his body*"*.* Thinking back about Louise's operation, her mother talked about her mixed feelings and said:

> "*It's been a double edged sword really, for her it's been the best thing, for me not [….laugh….] not so much. But it's not about me, so I don't regret it for Louise for one minute not at all.*" *(Louise's Mother – TP3)*

Rose's mother recalled that the tracheostomy had been "*a life saver*" and described how she has been able to "*come to terms*" *with* the tracheostomy because it was "*part of her now*"*.* Tom's mother was "*grateful*" that her son had a tracheostomy. For Tom's father it was the simple things in life that he had not appreciated twelve months ago that were important to him now, as he explained:

> “W*hen you think back to what we were doing this time last year. The simple things like the sun being out, the sky is blue. It’s like remember last year when it was sunny we were stuck in the hospital, the sky was grey for us and facing his trachy.*” *(Tom’s Father - TP3)*

In addition to thinking back, the parents also thought of the future. All the parents were hopeful for the future and this evoked different thoughts and feelings of hope. Facing the future was very important to parents and they shared their hopes of a brighter future for their child. Jack’s mother said she was “*hopeful for the future*” because Jack “*is doing so well*” and she talked of how Jack must face “*big surgery*” to repair his airway and how she is “*more excited to see how further he goes, so everything should go well I am very hopeful*”*.*

Other parents were looking forward to their child’s tracheostomy being removed. Sam’s father talked of his hope that one day his son’s tracheostomy might be removed and described this as “*the Shangri-La*”, although he also said he was “*quite happy with the way things are at the minute*”*.* Melody’s mother’s hope was that her daughter’s tracheostomy might be removed in the near future, and explained:

> “*I kind of hope and wish when we go to her next appointment, we get told the magic ‘D’ [decanulation] word, after we get an MLTB [scope of the airway] just to check it [airway] out. Then I think what I am going to do with a normal baby that actually talks [..laugh….]. So I’m not going to know what to do, I am going to have someone who will actually answer me back […laugh…].*” *(Melody’s mother - TP3)*

Freya’s mother had no worries or concerns for the future; she was content and “*feeling a lot more confident*”, and she explained, “*you know it’s just an extra thing to deal with, it’s not forever*”*.* She was confident that the tracheostomy would “*come out*”*.* However, Louise’s mother was pessimistic about the future; “*the last eight months we had no carers so a bit grim, I can’t see it changing*”*.* Louise had experienced many chest infections and unlike some other children her tracheostomy was for life. Louise’s care package had broken down again and this for her mother was a “*massive thing*” and a “*constant battle*”. However, she did acknowledge that “*Louise is fine and that’s the main thing. She has a future, so we are happy with that*”.

Tom’s parents explained that “*what was such a daunting prospect twelve months ago it’s unbelievable, what a difference a year makes*”*.* Tom’s mother thought that it would “*not be a disappointment*” if the tracheostomy did not come out in the immediate future, and how they were “*very much like taking it from day-to-day”.* The future with Rose having a tracheostomy did not matter to Rose’s mother because as “*long as Rose’s is here and as long as she is ok*”, that was all that mattered.

Conclusion to, ‘Looking back, looking forward’

Looking back and looking forward stories were concerned with how the parents reflected on their feelings about a tracheostomy twelve months on. Most of the parents were grateful that their child had a tracheostomy as this had allowed them to move forward into what they felt as easier times. Reflecting on the past allowed parents to see how far they had come and that a tracheostomy was the right choice for their child. Parents also looked to the future and most were hopeful that one day their child’s tracheostomy would be removed. However, none of the parents were in any rush for this to happen. They were content with managing their child’s tracheostomy and that their child had survived, and they were happy to wait for the right time for it to be removed.

The next chapter introduces and explores the theories of resilience which became the theoretical underpinning of this study.

CHAPTER 6: RESILIENCE THEORY

Introduction

The chapter addresses key literature on resilience, starting with a presentation of how resilience is defined. The origins of resilience research are discussed showing how these influence the ways in which it is studied. The literature addressing the nature of risk, vulnerability and protective factors within models of resilience is also presented and critiqued. Following this, a more in-depth consideration is presented on how resilience has been linked to the ABC-X model of family stress (Hills, 1949, 1958). This chapter will highlight the complicated methodological issues of studying resilience and how they are not easy to resolve. Throughout the past fifty years definitions of resiliency have been numerous and research has worked at different levels of analysis, each with its own language. This has made the complexity and application of resilience theory more difficult. However, Masten (2001) describes resilience as "ordinary magic" that emerges from the ordinary processes of normal human adaptation systems as a resource that withstands challenges that might otherwise overwhelm an individual, family or community. The next section will explore these issues in more detail.

Reflections on seeking my theoretical underpinning

Once my Findings chapter had been written, I needed to find a suitable supporting theoretical underpinning for my discussion. This took me on a journey that was very challenging. I found myself with a lot of concepts and literature to read and digest. I needed to relate these concepts to what I had already found out about the parents through their stories. I explored concepts such as motivation (Maslow, 1943, 1954), self-efficacy (Bandura, 1997) and cognitive adaption (Taylor, 1983). Whilst exploring and reading about these concepts I became aware that although they all had certain relationships to my findings, there was something missing in each of them that did not quite fit with the findings of my study. I made lots of notes about this exploration and at my next supervision session, I presented my ideas to the team and explained what I thought about each of these concepts and why I ruled them out. Eventually, I came to focus on resilience and after a long look at this concept and having read about many different perspectives and models I realised although it was a complex concept there was a strong relationship with my findings and I decided to take this forward as my theoretical underpinning.

Defining resilience

Over the past 50 years there have been many definitions of resilience presented and debated in the literature. Even with the vast amount of research conducted on resilience there is little agreement on a single definition and it is defined in a multitude of ways (Carle & Chassin, 2004). Despite shifts in how resilience has been defined over time, the principal factors of resilience tend to include the following:

- The person is said to be at risk if they are experiencing an adverse event that could involve an intense stress such as a life-threating or traumatic event.
- There is a development of a positive outcome; they move on to adapt positively.
- Through development the person rebounds from the stressful situation where they spring back into shape (Masten, 2001).

As previously discussed, the process is not straightforward or linear, not least because of the differences in the complexity of stressful experiences that create the challenges. However, one of the main difficulties in conducting research on resilience is that wide discrepancies exist in the way that resilience is defined and conceptualized. Masten (2007) suggests that many of the controversies surrounding the definition of resilience probably could be addressed by better science (rigorous attention to sharpening concepts, communication, and methodology). Rutter (1999, 2000) defines resilience as a dynamic process wherein individuals display adaptation despite experiences of significant adversity. Rutter proposes that resistance should not be expected to lie in a positive experience or that there are answers to what an individual does about a negative experience (Rutter, 2000). O'Dougherty et al. (2013) argued that resilience does not necessarily mean that an individual is unaffected or untouched by the adversity or that an individual faced with adversity will always function well. Easterbrook, Ginsburg, and Lerner (2013, p100) argue that humans' responses to adversity can vary tremendously and are part of a "dynamic developmental system". Resilience for the parents in this study was an ongoing, often dynamic process where they developed their personal abilities and cognitive strategies to respond to adversity.

Another disputed area is whether resilience is a characteristic, a personal quality or an outcome (Ahern, Ark, & Byers, 2008). Rutter (2007) suggests that resilience largely depends on mental operations, mediating processes that reflect personal agency, characteristic sets and the way people deal with challenges. Other researchers argue that resilience is a pre-existing trait (Connor, 2006; Richardson, 2002), but others insist that resilience occurs due to or results from a dynamic process of positive adaption (Roland & Walsh, 2006; Luther, Cicchetti, & Becker, 2000). This dynamic process aligns to Masten's (2001) proposal that generating resilience is a developmental process where individuals adapt and adjust to a traumatic experience. These interpretations of resilience will be explored further in this chapter. The next section highlights the concepts underpinning the four waves of resilience research and how the concepts of resilience are commonly understood.

Resilience and related concepts

Before looking at how resilience was demonstrated by the parents in this study, it is firstly necessary to address the overall concept of resilience and its wider literature. Resilience has been studied intensely in the past few decades by researchers from many different disciplines (e.g. psychologists, sociologists, psychiatrists, social workers and educators). Individuals, families and communities have been a source of interest for researchers studying resilience, including those working in areas such as psychopathology (Werner, Bierman & French, 1971; Garmezy, Masten, & Tellegen, 1984; Rutter, 1985, 1987; Masten, 2001; Masten & Narayan, 2012), children exposed to significant hardship (Anthony, 1974; Werner & Smith, 1982; Luthar, 2000), poverty (Day, 2009; Hossain, Byrne, Campbell, McKinley, & Shah, 2011), education (Luthar & Siegel, 1991) and divorce (Hetherington, 2003). Resilience remains a contemporary topic within both health care practice and research.

The concept of resilience has been explored in research on parents' experiences of having a child who has a mental illness (Dyson, 1997; Strecker, Hazelwood, & Shakespeare-Finch, 2013), and a disability or complex health conditions (Bitsika, Sharpley, & Bell, 2013; Mullens, Molzon, Suorsa, & Tackett, 2015). Interestingly, all of these studies define resilience in a slightly different ways, further demonstrating its complexity. For example, Bitsika et al. (2013) refer to resilience as an individual's capacity to cope with stress and resist its harmful effects, whereas Mullens et al. (2015) suggest that resilience is a process by which individuals learn to overcome the negative effects of risk exposure, cope with traumatic events and avoid negative adjustment outcomes. However, the challenges of profoundly stressful circumstances for the parents in these studies showed that having high levels of resilience acted as a buffer to stressful situations by contributing to adaptation and adjustment. According to Masten (2007) adaptation and adjustment have been considered as powerful systems of exploration in times of adversity. Masten suggests that there is promising work suggesting that in some cases, it may be possible to "reprogram" these systems to operate more normally when a positive caregiving or training environment is provided at times of adversity. The concept of resilience, particularly as part of community responses to disasters, referred to as "community resilience" (Cabinet Office, 2016; Organisation of Economic Co-operation and Development, 2014) has become a key government driver in UK and international policy. In the UK, the concept of promoting resilience in children and families policy has been to shape the philosophy to one of family empowerment, independence and stability.

Resilience: policy and guidance

In recent years, the concept of resilience has captured the attention of policymakers and institutions such as the Scottish government and organisations including the Joseph Rowntree Foundation. The challenges in the UK of an economic crisis at the end of the 2000s followed by an economic recession forced the government to think in new ways about policy and service delivery. The recession meant that healthcare and social services were challenged to deliver more for less and to do their utmost to improve services and outcomes for children and their families. Embracing the concept of resilience was seen as a step change in attitudes from dependent families to empowering families and prompting self-reliance. Resilience was seen by non-government organisations as a new philosophy to support empowerment and stability for families (Noyes, 2014).

Many voluntary organisations including Barnardo's (Glover, 2009; Newman & Blackman, 2002) and the Joseph Rowntree Foundation (Hill, Stafford, Seaman et al., 2007) have advocated the concept of resilience and produced guidance on how the concept of resilience can be applied to child care, vulnerable children and parents. The National Society for the Prevention of Cruelty to Children (NSPCC) advocates resilience as a learning strategy to help parents and children through tough times (Hart, Blincow, & Thomas, 2007). The NSPCC have organised forums and home projects to provide opportunities for families to learn and find out more about resilience to support their well-being and recovery.

An example of a resilience programme in action is the *UK Resilience Programme* which aimed to improve children's psychological well-being in school by building resilience and promoting accurate thinking. An evaluation of the programme showed short-term improvements in pupils' depressive feelings, improved school attendances and academic attainment in the subject of English (Challen, Noden, West, & Machin, 2008). However, the evaluation of the programme reported that the impact varied according to how often it was delivered and on the pupil's own characteristics. In England, *The Children's Plan* (DCFS, 2007) promoted the emphasis of resilience in children and young people as part of policy to improve well-being, but the plan did not make clear how this would be achieved, either by parents or professionals. There have also been examples of parental resilience programmes such as the Parent-Management Training model (Forgatch & DeGarmo, 1999, 2007) (see section Origins of resilience research, p204).

The Scottish government's interest in resilience is embedded in its policies and was first seen in documents such as *Transition in Lives of Children and Young People* (Newman & Blackburn, 2002). The Scottish government's policy on *Getting It Right for Every Child* (GIRFEC) promotes a resilience matrix that is now a central part of the Scottish government's integrated assessment children's policy framework (Scottish Government, 2008, 2012). This framework is for health professionals and agencies to structure and analyse information consistently to understand a child's or young person's needs. The document uses a matrix where resilience and vulnerability are seen as opposing constructs. The policy defines three building blocks of resiliency (secure base, self-esteem and self-efficacy).These are supported by resilience features: I have (social and interpersonal support), I am (inner strengths), and I can (interpersonal and problem solving skills). These features were drawn from the International Resilience Project (Grotberg, 1995). The International Resilience project surveyed almost 600 eleven year olds across 30 countries, and the theory behind the project states that a resilient child does not need all of the features to be resilient, but one feature is not enough. It also notes that children need resilient adults who know how to promote the concept.

Resilience projects and policies do not solely focus on specific populations (e.g. children); the concept of resilient communities is also a product of the government's agenda from devolving power, shifting from a top-down strategy to giving governance of health care and other matters to local councils and communities. Devolution Manchester (HM Treasury, 2015) for example, was given responsibility for their own health and social care budget which could benefit children. The Carnegie UK Trust has produced a handbook on community resilience which emphasizes the need for people to come together to "future-proof their communities on the basis of agreed values" (Wilding, 2011. p4).

Although it is clear that resilience has been advocated in many governments' polices, there is little policy and guidance on resilience for children and families with complex needs, which tend to focus on well-being and partnership working. The overall message of resilience needs to be embedded in practice by professionals who deliver care to children with complex needs and their families, guiding them to become resilient within the context of their own lives. The Chief Medical Officer (2013) proposed that resilience varies in detail within health and social care policy and the expectation of how professionals will implement the concept. Noyes (2014) notes that it is yet to be determined if the policies actually achieve their anticipated outcomes because there is a variance in the tools utilised to promote resilience. Noyes suggests that resilience needs to be measured effectively, and professionals in health and social care need the appropriate skills and knowledge to make changes in their practice to promote resilience. As governments confront substantial health care challenges, the growing knowledge-base on resilience could be vital in guiding policy that could improve children’s and parents’ health and well-being.

It is crucial that policy is effective, easy to implement and proper resources are provided to professionals to make the changes needed so that they can monitor the outcomes of resilience in children and their families. Although the ground work has already been done by leading UK children’s charities, all four governments need to listen to what is effective and what works for children, particularly for children with additional and complex needs who require ongoing and sustained care. Planned care for children with long-term and complex conditions often takes second place to children with less complex health needs (Wolfe, Lemer, & Cass, 2016).

The next section will explore the origins of resilience and how the concept has progressed.

Origins of resilience research

Resilience studies have been conducted and have progressed within four major waves of research (Masten, 2007). In this chapter, I draw attention to the concepts and findings resulting from these waves of research and how the complexity of this structured approach has been challenged. Masten (2007) claims there are four distinct waves of resilience research (see Table 6.1) and states they are important, because they suggest the growth of ideas and concepts surrounding resilience in these fields. The waves signify a shift in focus from individual characteristics of resilience, to a focus on more complex interactions in society and the family, through to resilience research being seen as a dynamic multilevel analysis of systems.

Table 8: Masten's (2007) four waves of resilience research.

Waves of resilience	Views of resilience	The focus of resilience
The First Wave	Attributes of the individual despite risk: the focus centres on attributes specific to the individual, such as personal qualities, capacities, skills and abilities that were associated with positive adjustment despite exposure to risk factors.	Characteristics of individuals
The Second Wave	Included the focus on relationships of resilience: Introduced protective and risk factors definitions characterised by concepts such as processes, patterns, vulnerability, risk and protection.	Relationships
The Third Wave	Systematic approach of interventions that foster resilience: More systemic understanding of resilience which referred to dynamic processes systems and negotiation, thus promoting wellness and competence	Influence of society
The Fourth Wave	A multi-level ecological understanding of resilience. An ecological understanding of resilience places individuals and adversity. Characterised by a focus on multilevel analysis and the dynamics of adaptation and change	Complex systems

One of the challenges in understanding resilience is its conceptual complexity and the variety of opinions on the subject. Manyena (2006) discusses that the theory of resilience and its application is not rosy and is contested. Resilience research has been talked about as being neatly packaged within the four waves (Masten, 2007; O'Dougherty-Wright et al., 2013) when actually it is quite complicated and contested by other researchers who do not see these waves as being clean and tidy (Luthar & Cicchetti, 2000; Richardson, 2002; Windle, 2011).

One area of confusion is the understanding of the second and third waves of resilience research. Some authors ascribe the second wave of resilience inquiry as a dynamic process and positive adaptation (Gillespie, Chaboyer, & Wallis, 2007; Rutter, 1999), whereas Masten (2007) would focus the second wave on relationships of resilience and ascribe the dynamic processes that foster resilience to the third wave. Some authors see the third wave as an innate life force within an individual (Butler, 1997: Waite & Richardson, 2004) which totally contradicts Masten's view of the third wave having influences on society. From my reading, I argue that these waves are blurred and there is overlap in their meaning and application. For this reason, I have not chosen to position my thinking within the four waves of resilience research as they are challenged and this makes this unhelpful and ambiguous. Therefore, I have not framed this theory chapter within the four waves, but rather I present an unfolding and emerging picture of the different approaches.

The first seminal resilience research emerged in the 1970s and 1980s and focused on individual strengths and predictors of positive adaptation against a background of adversity (Anthony, 1974; Werner & Smith, 1977). The majority of resilience research at this time was undertaken within the subject of psychology and was mainly focused on children**.** Werner and Smith (1977) commenced a four decade longitudinal study into high-risk children on the island of Kauai; the aim was to follow the course of all pregnancies and their outcomes in the entire community from birth to adulthood. A team of mental health workers, paediatricians, public health workers and social workers monitored the development of all children born on the island from the age of one through to the age of forty. This unique opportunity examined risk and recovery factors, and a striking finding of this study was that most of the high-risk youths who had developed an inability to cope in adolescence had staged a recovery by the time they reached midlife (ages 32-40 years) (Werner & Smith, 2001). During the early resilience research, researchers tended to regard and label individuals who transcended their adverse circumstances as "hardy", "invulnerable", or "invincible" (Anthony, 1987; Werner & Smith, 1982). However, such labels implied that individuals are incapable of being wounded or injured and Garmezy (1993a) cautioned against the use of these terms.

Underpinning the rationale for many investigations into resilience were the seminal studies of children considered at risk due to parental schizophrenia, but many of whom were found to thrive despite their high-risk status (Garmezy, 1971, 1974; Garmezy et al., 1984). Garmezy (1974) first proposed the existence of "protective factors" that could enable an individual to cope after a stressful event and that would support their positive development. Garmezy et al. (1984) suggested that social competence and attentional factors were the dependent variables that would help a child's competence and serve as a protective buffer against developing a behaviour disorder. Garmezy was interested in what experiences meant for individuals and how research findings might be used to develop better means of helping children who experience serious stress and adversity.

Due to these studies a number of programmes adopting different approaches to alleviating the consequences of adversity in children were later developed. These programmes became an incentive for exploring adversity widely (Cicchetti & Rogosch, 2007; Curtis & Cicchetti, 2007; Luthar, 2006; Martinez-Torteya, Bogat, Voneye, & Levendosky, 2009); these researchers were interested in developing interventions and programs to prevent risk for a range of maladaptive health and behavioural outcomes for children. For example, in one of these studies Cicchetti and Rogosch (2007) examined maltreated and non-maltreated children and their resilience to adaptive functioning. These authors focused on the contribution that personality features have to resilience and coping under adversity.

As resilience research evolved, it has focused on the understanding of relationships and their dynamic processes. As a result of experiencing adversity, an individual displays positive adaptation despite experiencing a misfortune (Rutter, 1999). This conceptualisation recognised resilience as a process and not a single event (Richardson, 2002). This then led to greater emphasis on the external factors and systems that influence adaptation and led to a better resilient outcome. As a result, studies of resilience explored further how individuals interact with many other systems at many levels throughout life.

As researchers continued to learn more about resilience, it became evident that there was a shift towards promoting the concept. Researchers investigating resilience focused on the positive adaption to introduce preventative measures for those individuals at high risk of developing problems. This was represented by a coming together of goals, models and methods on avoidance and how resilience can occur naturally (Luthar & Catendresse, 2005). Positive adaptation and transformation allow for reframing of stressful experiences whereby the experience is no longer viewed as stressful, with personal changes and positive meaning being attributed to the experience (Tebes, Irish, Puglisi-Vasquez, & Pekins, 2004). Therefore, timing of an intervention can lead to positive outcomes and this can be important in the longer term in avoiding maladaptive behaviour. For example, the Parent-Management Training model (Forgatch & DeGarmo, 1999, 2007) describes a manualised parenting programme for parents whose children have conduct issues, through which five key skills are promoted: skill encouragement, setting limits, monitoring, problem solving and positive involvement. A follow-up study revealed a higher standard of living and healthier social interactions nine years after the intervention (Forgatch, Patterson, DeGarmo, & Beldavs, 2009). A critical challenge at this stage of resilience research was the need to address underlying systemic and structural issues and not just target individual and specific risk factors.

In more recent times, resilience research has sought to integrate studies using different concepts so that a better understanding of these complex processes can be achieved. Resilience is now being explored through psychological, biological and social research and the research involves a focus on the interaction of individual and environmental characteristics (Hoge, Austin, & Pollack, 2007; Kim-Cohen, 2007). Richardson (2005) discusses that integration of the personal and environmental components of resilience promotes the more holistic examination of the concept of resilience by positioning resilience research as an interdisciplinary endeavour. In material science, resilience refers to the ability of something to return to its original form after being bent or compressed. This has been associated with the plant bamboo, which can be bent to the ground but spring back healthy and strong, and essentially unchanged (Smith et al., 2008). I argue that the parents in my study do not return to precisely the same original position they were in before their child needed a tracheostomy, but to a new configuration to fit their new environment (Abel

& Stepp, 2003; Trosper, 2003); this involved a transformation and response to the new and numerous challenges. This concept was evident in my study as the parents' reactions to the magnitude of their adversities were to draw upon their own characteristics and various resources to facilitate adjusting to their child having a tracheostomy.

In summary, the concept of resilience is complex. Therefore, this makes it a considerable challenge to define resilience and understand how work surrounding this concept has developed. Linked to the work around resilience are the concepts of risk, vulnerability and protective factors. The next section will explore and unpick these factors in greater depth and the relevance they have to this study are examined.

The nature of risk, vulnerability and protective factors

Various resilience theories have emerged to explain risk, vulnerability and protective factors. Risk, vulnerability and protective factors remain key terms associated with resilience research (Gomez & Brown, 2007) and these terms best reflect the different variables under investigation that are thought to influence the course of individuals' adaptation or lack of adaptation (Zolkoski & Bullock, 2012). Newman (2004) reviews the factors and their relationships that contribute to building resilience and proposes the following; risk is any factor or combination of factors that increases the chance of an undesirable outcome affecting a person; vulnerability is a feature that renders a person more susceptible to a threat; protective factors are the circumstances that moderate the effects of risk.

Risk is viewed as a forceful process, and response to risk varies among individuals and their life context (Cowan, Cowan, & Shulz, 1996). The concept of risk includes the notion of cumulative stress. Cumulative stress is characterized by the accumulation of various stress factors such as poor communication, coping with situations in which you felt powerless, and the inability to rest or relax (McSteen, 2012). Stress has been distinguished from risk and is proposed as being the individual's subjective reaction to life events that require adaptation (Garmezy, 1993b; Masten, 1994). The process of defining and examining risk factors has proven to be a challenge for those studying resilience. Howard, Dryden and Johnson

(1999) state that a potential problem with resilience research is that researchers assume that all participants share the same understandings of risk and resilience. Therefore, it is important that researchers have a shared understanding of what risk is.

Condly (2006) suggests that when describing the nature of risk it is crucial to understand how it affects people and how resilience operates. Condly describes risk as multi-faceted in nature and the nature of risk and its understanding is crucial in how it affects people, and how resilient people function. Egeland, Carslon and Stroufe (1993) discuss the effects of risk as cumulative and that these effects increase with the passage of time. As the various risk factors build up there is a surge in pressure on individuals and resilience can be seen as a positive response to the risk. To diminish the risk and its impact, protective factors play an important part in an individual's recovery.

Protective factors act to prevent risk or moderate or buffer the effects of risk, and are part of the ongoing process that helps an individual adapt to life stressors (Luther & Zelazo, 2003). Individual or family protective factors may include communication, self-efficacy, openness, traditions, presence of supports and ability to deal with ambiguity or the unknown (Yorgason, 2010). When a positive judgement is described as a protective factor, some type of safeguarding from the effects of risk or adversity is implied. The nature of the interplay of risk and protective factors continues to be debated among researchers (France & Utting, 2005). Masten (1987) argues that risk and protective factors are opposites, in which competence decreases as stress increases. However, Rutter (1993) suggests that risk and protective factors interact to produce an outcome however, when stress is low, this means protective factors are of less influence. In summary, risk, vulnerability and protective factors are important features within resilience research that help explore and explain how individuals face, adapt and adjust to adversity. In the next section attention is given to the different models of resilience and how they have developed.

Exploring models of resilience

Numerous different theoretical models of resilience exist. In this section, different types of resilience models are considered and critiqued in light of my search for a model to help frame the discussion of my findings.

Masten (2011) maintains that models play a significant role in describing the conceptual frameworks in resilience research. From within the literature an abundance of models have been used to explain the concept of resilience. These models have evolved over the years to reflect the fact that the general knowledge- base of understanding resilience has changed. There are two main models - resilience variable focused models and person focused models - both of which have described elements of resilience and how these relate to risk, positive adaptation and other influences such as protective factors (Prince-Embury & Saklofske, 2013). However, I also chose to explore family-focused and coaching models as they seemed to have a connection to my findings.

Variable focused models

Variable focused models attempt to find out what accounts for positive outcomes connecting individuals and environments, and different experiences, and are appropriate for considering protective factors and the impact they have overall on the risk under investigation (Masten & Reed, 2002). Variable focused approaches use multivariate statistics to examine the relationship between adversity, outcome and the protective factor(s). Garmezy et al. (1984) used this type of model when exploring the relationship between stress resistance and adaptation in children with disabilities by focusing on risk-competence and protective factors. Garmezy and colleagues presented a three-way model approach which consisted of compensatory models, challenge models and protective-vulnerability models**.** Compensatory models explore how the risk is defused by protective factors, challenge models observe that moderate levels of risk are linked with less negative or more positive outcomes, and protective-vulnerability models show how resources affect or reduce the risk of a negative outcome. According to Garmezy et al. (1984) these three-way models are not mutually exclusive but they may be mutually combined. However, each model serves to show how a major crisis evolves and what forms of relationships occur between personal attributes and stressful circumstances and how individuals adapt.

Garmezy's three-way model approach has been utilised in many studies, with the models either being applied together or separately (Schmeelk-cone, Zimmerman, & Abelson, 2003; Zimmerman, Ramirez, Washienko, Walker, & Dyer, 1995). An example of this is Zimmerman, Steinman, and Rowe's (1998) study which used the compensatory model to explore violence among adolescent children**.** This study found that parental support compensated for and offset the risks associated with fighting and being around violent adults and resulted in less violent behaviour in adolescents**.** Fleming and Ledogar (2008) reviewed cultural resilience in Aboriginal communities using the three-way model (compensatory, challenge and protective-vulnerability models), which was applied to add additional concepts on resilient reintegration and a new level of growth to awaken resilience in Aboriginal communities. Theorists have elaborated these three basic models (Luthar, 2006; Masten, Cutuli, Herbers, & Reed, 2007) focusing on different pathways after trauma (Masten & Narayan, 2012) and the role of early resilience on long-tern developmental outcomes (Masten & Cicchetti, 2010; Masten, Desjardins, McCormick, Kuo, & Long, 2010).

Person-focused models

Person-focused models aim to identify comparative groups of individuals who have experienced similar high levels of adversity and who show patterns of good or poor adaptation, so as to recognise the factors that might lead to risk or strengths (Masten, 2001). Person-focused models tend to identify resilient people and understand how resilience develops by comparing them to non-resilient people who are not faring well in the face of adversity. For example, Bucker, Mezzacappa and Beardslee (2003) examined 155 youths and classified 29% as resilient. The non-resilient youths experienced more negative life events, chronic strains and abuse, whereas the resilient youths had greater self-regulatory skills and self-esteem and received more active parental monitoring. Person-focused models can be seen to have significant advantage over other types of models when studying individuals' lives through time compared to just one moment in time (Masten & Reed, 2002).

Coaching models

Coaching models provide a framework for guidance, and their underlying structure is for a person to coach someone to aspire to certain attributes (Cortes, 2015). Kenneth

Ginsburg (2011), an American paediatrician, developed a coaching model on positive youth development in 2006. His model aims to provide parents with a foundation to prepare their children to become healthy productive, contributing adults who are resilient in society. Parents are provided with a set of seven ingredients that are called the 7Cs: competence, confidence, connection, character, contribution, coping and control as building blocks of resilience to apply to life and its challenges. Ginsburg discusses how parents need to prepare their children to cope with difficult challenges and to be able to progress and equip themselves to succeed despite or even because of the challenges they faced. Ginsburg (2011) proposes three fundamental principles to achieve this; emphasising the strengths of children, empowering children and encouraging children to be self-motivated. Despite being used in different areas of research such as child anxiety (McLain, 2007), the military youth (Easterbrook, Ginsburg, & Lerner, 2013), and play intervention (Garnett, 2014), there is no evidence that this model has been empirically tested (Garnett, 2014). Some authors argue that the authentication of the model itself may not be essential as the core components are already well-established concepts in the larger body of the resilience literature (Masten, 2001; Zolkoski & Bullock, 2012).

Family-focused models

The concept of family-focused models is based on risk, protective mechanisms and positive adaption (Patterson, 2002). A family resilience framework can serve as a valuable conceptual map to guide prevention and intervention efforts to support and strengthen vulnerable families in crisis (Walsh, 2003). The ABC-X model of family stress was first proposed by Hill (1949, 1958), and this model laid the foundations for all subsequent family stress research and family resilience models (McCubbin & Patterson, 1982). The original model was slightly modified by Hill in 1958, and McCubbin and colleagues have refined, expanded and developed the ABC-X model of family stress adjustment and adaptation. These adaptations to the ABC-X model are:

- The Double ABC-X Model - Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & Patterson, 1982, 1983a, 1983b).
- The Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988).
- The T-Double ABC-X Model (McCubbin & McCubbin, 1987, 1989).

The ABC-X model and its adaptations warrant further exploration, and the next section will consider Hill's (1949, 1958) ABC-X model in more detail and how it has further developed.

An overview of the ABC-X model

This section will focus on the origins of the ABC-X model and how this model has evolved. An exploration of the model will show how it has developed to allow researchers to investigate complex issues for families and how they have adapted and adjusted to stressful situations. In the next section a critical consideration of the development of the ABC-X model is presented and discussed.

Hill's model of ABC-Model of family stress

Reuben Hill, a social scientist (1949, 1958), first conceptualized a crisis theory that applied to families who had experienced separation and reunion as a result of World War II, and his classic ABC-X model of family stress looked for factors which contributed to family survival. The framework for the ABC-X model is as follows: The event or stressor (A) interacts with the family resources (B) and with the definition the family makes of the event (C) for dealing with the crisis (X). These factors were formulated into what Hill called his ABC-X model of family stress. However, not all families' progress to the point of a crisis in which the family's function alters and re-organization is necessary. The ABC-X combination of Hill's model are descriptive accounts of family functioning in the face of adversity, and depict which families deteriorate into a crisis and which families do not. These are presented in more detail in the next section.

The A factor

The A factor (the event/stressor) highlights how an event causes a family to face adversity. This adversity impacts upon the family unit which produces or has the potential to produce a change in its function. The severity of the stressor is determined by the degree to which the stressor threatens the stability of the family unit or places significant demands on the family's resources and capabilities. Hill (1958) describes four main classifications of stressors:

- Accession - a change in the family structure (birth)
- Dismemberment – a change due to loss of a family member (e.g. child’s death)
- Loss of family morale and unity (e.g. drug or alcohol use)
- Changed structure or morale (e.g. divorce)

The B factor

The B factor (the resources) refers to the family’s internal and external resources. Hill (1949, 1958) speculated that if families had the ability to prevent the stressor or event, or have the right support in place, this would reduce the impact of the crisis. The goal of adjustment is to manage the stressor without introducing major or lasting changes in the family’s established patterns of functioning. Resources then become part of the family’s capability and capacity for resisting crisis and promoting family adjustment.

The C factor

Hill's C factor (the perception) determines how the family perceive the impact of their situation. This complex factor refers to the shared family understanding or opinions held about the stressors and the extent to which the changes are perceived as a disaster or an opportunity. Hill (1958) suggested that the meaning a family gives to an event is affected by three key factors: the family’s value system, previous definitions used (from impartial observers, from the community or society where the family lives, or view of the family itself) and previous experiences in handling crises. Hill maintains that the family’s personal definitions are the most important for influencing its response to the crisis.

The X factor

The X factor of Hill’s model relates to the family crisis and depicts the point at which the family is disrupted. Hill (1958, p6) defines the crisis as “any sharp or decisive change for which old patterns are inadequate”. The crisis is considered to be a disruption in the family’s routine, and the bigger the disruption, the greater the degree of the crisis; hence, X can refer to the extent of the crisis. The stressors, resources and perceptions of the event (ABC) delivers X the outcome of the crisis. Hill discusses that the likelihood of family stress was dependent on not only the stressor but also the family’s ability to work together and use resources to deal effectively with it (Hill, 1958).

Figure 6.1: Hill’s ABC-X Model of family stress.

(B) Internal Family Resources &
Informal/Formal Social Supports

Family (A) --> Family Crisis (X)
Stressors
(C) Family Perception &
Parental Self-Efficacy

Within the ABC-X model families are expected to follow a roller-coaster course of adjustment with a trajectory of crisis, disorganization, readjustment and recovery (Hill, 1949, 1958). Hill discusses protective factors at work within the family that help buffer against the negative consequences of sudden stress; he relates these to the B and C factors of the model.

Hill’s research and his ABC-X model focuses on families, but the concepts of the model may be applied to individuals (Boss, 2002). Hill has made a significant contribution to the field of family stress and family resilience research. Through providing guidance on how to enhance the resilience of families through the resources and perceptions that are in their control, it offers a framework within which to classify the findings of later research looking at families’ strengths. The 70 year old model has inspired an abundance of research and has remained more or less relevant today (Weber, 2011). However, Hill’s model has been criticized for not explaining adaptation to stress (Boss, 2002). Other researchers have adapted Hill’s model to explain how families can bounce back from a crisis situation, (Burr, 1973; McCubbin & Patterson, 1982, 1983a, 1983b). Burr (1973) changed Hill’s formula by developing the concepts of vulnerability (the ability of the family to prevent a stressor from precipitating a crisis) and regenerative power (the capacity of the family to recover from crisis) as contributors to how families adapt. Building on Burr’s model, McCubbin and Patterson (1982, 1983a, 1983b) were the first researchers to introduce the Double ABC-X model and the next section presents a review on how this model has been developed further.

The Double ABC-X Model - Resiliency Model of Family Stress, Adjustment and Adaptation

The ABC-X model was refined through the inclusion of additional factors such as a family's social context and further developed into the Double ABC-X model which is also called the Resiliency Model of Family Stress, Adjustment and Adaptation, (McCubbin & Patterson, 1982, 1983a, 1983b). The Double ABC-X model addresses post-crisis coping and processes that determine whether a family can adapt to a crisis. The Double ABC-X Model emphasises adaptation that relates to the family schema level of appraisal (how they cope) as a force that can facilitate family coping and adaptation (McCubbin & McCubbin, 1996). This Double ABC-X model varies from the ABC-X model by questioning how the family recovers. The model comprises of two distinct parts: the adjustment phase and the adaptation phase. Each phase describes the family's ability to cope with stress or illness by looking at its strengths and resources.

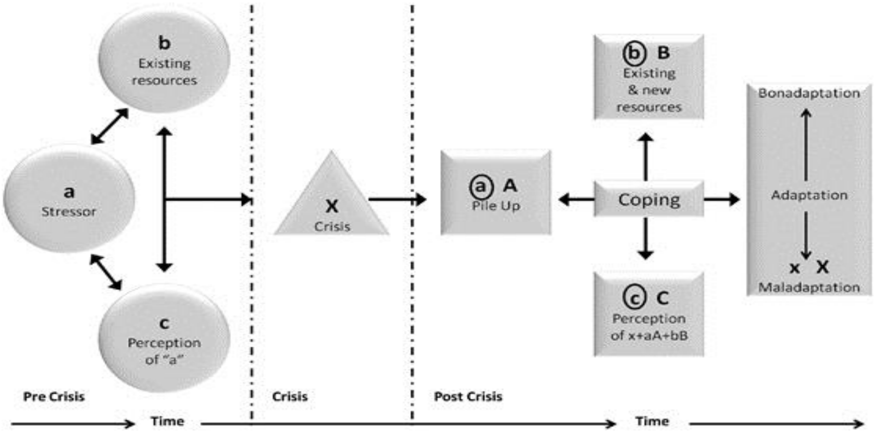


Figure 6.2: The Double ABC-X Model (McCubbin & McCubbin, 1996)

The Double ABC-X model has taken the concept of resilience and family coping forward in a number of ways by adding post-crisis variables in an endeavour to describe key features. These key features include the following: additional life stressors and strains which influence the course of family adaptation; the critical psychological impact and social resources families draw upon and employ over time in managing crisis situations; the changes in definition and meaning that the families develop in an effort to make sense out of their situation; and the coping strategies families employ with the range of outcomes of these family efforts. Also introduced within the Double ABC-X model is the notion of time and how families change over time (McCubbin & Patterson, 1983b). McCubbin and Patterson discuss how families appraise their situation by moving through the crisis to increase adaptation and that their demands change over time.

Boss (2002) claims that the Double ABC-X model needs developing further because it lacks attention to the unpredictability of experiences to the family or individual members. The Double ABC-X model is static in nature and the process behind the family's actual participation in adjustment is not clear. The model simply describes the structural relationships between various factors and does not address the processes (Smith, 1984). Another criticism of the Double ABC-X model is that the crisis refers to the family's inability to prevent change, whereas Smith (1984) argues real crisis comes from within a family's inability to change an adverse event.

Further adaptation to the Double ABC-X Model

The Family Adjustment and Adaptation Response (FAAR) model evolved as a natural extension to the Double ABC-X model (McCubbin & Patterson, 1983a) with an emphasis on describing the processes involved in the family's efforts to balance demands and resources. The FAAR model focuses on three systems; the individual, the family, and the community, by highlighting the family's efforts to maintain balanced functioning by using its capabilities to meet its demands (Patterson, 1988). This model depicts both protective and recovery patterns of family functioning that predict adjustment and adaptation. DeMarco, Giboe, Friedemann, McCubbin, & McCubbin (2000) argue that families in their study did not always progress in a direct linear fashion through the entire FAAR process from crisis to adaption. It is possible family's can 'get stuck' at one phase, and could revisit earlier phases to achieve adaptation (DeMarco et al., 2000)

In 1987, McCubbin & McCubbin introduced the T-Double ABC-X model (known as the Typology Model of Family Adjustment and Adaptation), which was further refined by them in 1989 as a means to describe the processes that families undergo when experiencing pre-crisis adjustment and post-crisis adaptation (McCubbin & McCubbin, 1987, 1989). The T-Double ABC-X model adds more of a focus on assessing family functioning and intervening in the family system to facilitate both family adjustment and family adaptation.

Ellingsen and colleagues' version of the ABC-X Model

Ellingsen, Baker, Blacher, and Crnic's (2014) longitudinal study on resilient parenting of pre-school children at developmental risk developed their own adaptation of the ABC-X model. The conceptual model examined factors that promoted effective parenting. These included the following:

- A - Level of risk (family income, child behaviour problems, child developmental delay)
- B - Resources (mother's education and health)
- C - Cognitions (mother's optimism)
- X - Outcome of interest (positive parenting)

The focus of this version of the ABC-X model was to explore positive parenting by mothers of a child with developmental delay and present the risk factors of child characteristics and family economic resources, and what protective factors contribute to positive parenting. These protective factors were theorised as, mother's education, maternal health and optimism. Their version of the ABC-X model showed a shift towards an exploration of the following:

- The X domain was depicted as a positive response to the risk.
- C domain was presented as cognition instead of perception, to further explore how a mother's optimism would buffer the risks of having a child with developmental delay that would lead to positive parenting.

Ellingsen et al. (2014) hypothesised that higher levels of resources and cognitions would buffer the A-X relationship. They also discuss how this model allowed for an exploration over time of the ups and downs of parenting. Summers, Behr, and Turnbull (1989) propose that the concepts within the models of the ABC-X and Double ABC-X are truly beneficial to understanding how families move through time, as well as change and adapt in response to a stressor/crisis event. The changes made by Ellingsen et al. (2014) to the ABC-X model had a strong connection to my findings and became the main theoretical model underpinning my discussion chapter.

Selecting a model which underpins the concept of resilience in my study

In looking for a theory to inform the discussion of my findings, I looked at three types of models of resilience. Variable focused models give consideration to protective and risk factors (Garmezy et al., 1984) and therefore have some resonance with my findings. However, my study did not intend to examine the specific combination of risk factors or pinpoint assets implicated in achieving good outcomes when facing adversity. Thus, the variable focused model was not appropriate for my study. Person focused models linked into my study due to their study of individuals over time (Masten, 2001). However, on further exploration, person focused models were not seen as having a good fit because comparisons between the same individuals over time was not a focal point of my research. Coaching models were also explored as a possible model to underpin this study. Ginsburg's (2006) coaching model, the 7C's model of resilience on youth development, initially appeared to be a useful approach to frame the discussion of my findings. However, when this model was explored further and applied to some of the findings of this study, it did not provide a strong enough framework to develop the protective and risk factors of resilience which are focal points of my study. This was because Ginsburg's coaching model was a guide for a prospective process as opposed to an explanatory model for previous experiences.

The ABC-X model of family stress and coping is used to explore stress and coping within families and was identified as a suitable model which might have value to underpin the discussion of the findings from this study. Hill's (1949, 1958) ABC-X model is a model of resilience and is the basis of most family stress models (Ingoldsby, Smith, & Miller, 2004; Weber, 2011). The ABC-X formula (Hill, 1949, 1958) emphasises that the stressors (A) and the family's resources (B) intersect with the meaning (C) that families apply to stressors to produce a crisis (X). Families may define stressors as positive or negative depending on the reactions or outcomes of the stressor. Hill’s model was further adapted into the Double ABC-X models by McCubbin and Patterson (1982, 1983a, 1983b) in order to answer pre-crisis variables, which are both linear and deterministic.

Ellingsen et al.’s (2014) longitudinal study focussed on resilient parenting of pre-school children at developmental risk and resulted in an adapted version of the ABC-X model. Ellingsen et al.’s version of the ABC-X model explains how risk factors can be buffered by protective factors to achieve an outcome of interest (see Chapter 6 on Resilience theory for more detail). The reason for selecting Ellingsen et al.’s model was to frame the discussion of my work. The terminology and the values of this adapted version of the ABC-X model had a good association with my findings and seemed useful in its potential to apply to clinical practice.

Conclusion

This chapter has discussed the theoretical concept of resilience and acknowledged its complexity. Over the past several decades researchers have used the concept of resilience as a way to study the processes through which exposure to risk factors may be associated with positive outcomes. It appears from the literature that risk and resilience theory could serve well as one of the major theoretical underpinnings of human behaviour (Greene, Anderson, Hetherington, Forgatch, & Degarmo, 2003). The ways in which risk and protective factors interact can be explored through models of resilience. In the discussion chapter of this thesis I will propose further development of an existing model of resilience, discuss how this was developed and explain how this helps frame the experiences and resiliency of parents whose child had a tracheostomy.

CHAPTER 7: DISCUSSION

Introduction

Nine parents participated in this longitudinal narrative study and were interviewed over the first year of their child having a tracheostomy. In exploring and interpreting my findings, I discovered that over time parents of a child with a tracheostomy learnt to reframe their lives; this reframing was central both to their experiences and to how they developed resilience to the adversity they faced. Despite the profound life and death challenges their child experienced due to their breathing difficulties, the parents learned to face and overcome challenging times. The findings revealed that the parents in this study experienced shock, emotional upheaval and uncertainty about their child's condition. Against this background of challenges parents had to make many tough decisions; some of these decisions were at a time when they had fears about the immediate future of their child's life, while other decisions occur occurred later as they learned to care for their child with a tracheostomy.

As their child's health condition settled (post-tracheostomy) life became calmer and parents showed the capacity to function by reframing their beliefs and developing a new understanding about their lives. However, once their child was discharged home some parents experienced new pressures and challenges in trying to reframe their lives and care for their child at home. In this chapter, I will explore and discuss the stories told by the parents, focusing on the concept of resilience to better understand its role in parents' experiences of their child having a tracheostomy.

Parental resilience in this study

The development of parental resilience was a process and a journey that was associated with times of stress and how the parents responded to these times of stress. As seen in other work, the parents' resilience was built over time, reflecting their use of internal and external resources at times of adversity (Schofield, 2001; Yates et al., 2003; Rutter, 2012). At given points in their journey, and in the way

Masten (2001) proposes, they were able to manage adversity and thus they demonstrated that they were resilient. The risk and protective factors (which were a focus of this study) operated in different ways at different time points throughout the parents' journey and, as proposed by other authors (Garmezy et al., 1984; Rutter, 1985: Smith-Osbourne, 2009), led to different consequences. For example, at the start of their journey, they had fewer protective factors related to their child's condition that they could muster to help deal with what they perceived to be a major risk and stressor (their child needing a tracheostomy). The need for their child to have a tracheostomy challenged their personal resources and they framed this as something over which they had little control. However, over time and as their cognition shifted from negative to more positive feelings and the risk was seen to be manageable, they reframed their thinking and perceptions and started to build their resilience. As parents developed skills and confidence in managing their child's tracheostomy, they had more protective factors to draw on and the perception of their stress was lower.

The parents were able to reflect and recognise that there were times when they exhibited higher levels of resilience and times where their resilience was lower. Clearly resilience was a dynamic process. The parents were constantly challenged and stretched but despite this they were often able to find within themselves greater strength that they expected and were able to display greater levels of resilience as they faced and managed new challenges (such as changing their child's tracheostomy tube for the first time). The parents' cognition of new risks often resulted in them initially feeling shocked, but they were able to draw upon their experiences of knowing what they had previously overcome and they were able to reframe these situations; this helped further build their resilience. As they became more resilient about aspects of their child's care and condition, they were able to move forward and take more confident action with regards to their child's health care and developmental needs.

However, there were moments and situations which overwhelmed them and at these times their protective factors were insufficient to support their usually resilient approach. Regardless of these dips in resilience, on the whole over the

12 months there was a sense that parents were becoming more resilient in relation to the various challenges of being parents of a child with a tracheostomy. As the parents managed each new different experience successfully they appeared to become more predisposed to managing the next challenge. Resiliency has been described as being like muscle that must be developed and consistently exercised (Wilding, 2014), and this was evident in this study as parents used their emotional muscle to be strong enough to withstand severe challenges, and flexible enough to withstand a wide range of unpredictable forces.

The findings of my study suggest that although parents were starting to build resilience when their child was in hospital, they continued to develop resilience across the whole of the 12 months of the study. Being in hospital, particularly in the early days, involved parents having to face considerable challenges albeit that they were in an environment where they were gaining support with meeting their child's needs. Being at home with their child appears to be favourable to them building resilience. This is a positive finding in the light of the high costs associated with delivering care to children and their families within both hospital and home settings. What is impressive is that parents are able to build resilience at home, especially considering the fact that it was clear that community-based care is not perfect and that services are not streamlined (Carter at al., 2014). Being at home is not '*easy*'; parents continue to be challenged not only by their child's changing needs but also by the need to '*battle*' for services, as seen in other studies addressing the care of children at home (Watson et al., 2002; Townsley et al., 2004; Miller et al., 2009; Callans et al., 2016). The degree to which support from health and social care professionals helps builds resilience has not been the focus of this study. However, it is clear that parents value the support available to them and that they appreciated appropriate support such as respite care. What is even clearer is that parents' resilience is challenged when support structures such as packages of care fail. Supporting parents through their journey of having a child with a tracheostomy is not only essential to meet the clinical needs of the child, but this study suggests that it is important to support parents' needs and the creation of conditions to help support resilience. Quite what it is about being at home that supports parents to build resilience is tricky to identify, but the opportunity to be '*a family'* and to work out solutions and build confidence all seem to be factors which contribute to the success that is evident in the families in this study. The literature reflects that the parents of children with complex needs require support at home (Kirk & Glendinning, 2002; Narramore, 2008; Hewitt-Taylor, 2009b; McCann, Bull, & Winzenberg, 2012; Nicholl & Begley, 2012; Whiting, 2014).

In the following section, I present my model, which is based on Ellingsen et al.'s (2014) conceptual model of child risk and parenting outcomes, with others' resources and cognitions as protective factors. The model developed which underpins my study is called the 'The ABC-X model of parental resilience and reframing'.

Developing the ABC-X model of parental resilience and reframing

The 'ABC-X model of parental resilience and reframing' underpins the discussion of my study, and is based upon Ellingsen et al.'s (2014) ABC-X model. This model allowed me to explore and conceptualise the process of resilience that was demonstrated by the parents in my study. Resilience is an important concept because it explains the parents' process of reframing when their child had and then lived with a tracheostomy. The model draws upon the four domains of Ellingsen et al.'s (2014) model which are: (Domain A) the level of risks (which fluctuate), and (Domain B) resources, and (Domain C) cognition (both utilised as protective factors) that parents draw upon to achieve a response, (Domain X) reframing.

In my presentation of the 'ABC-X Model of parental resilience and reframing' I also draw on some elements from McCubbin and Patterson's (1983a) 'Double ABC-X model'; the elements I weave in to my model are situational demands, pile-ups and how demands of individuals or communities change over time. These elements were important to include because they developed the model further and will be covered using the following terminology: situational demands (will be covered as intense risk), pile-ups (will be covered as accumulation of risk), and demands that changed over time (will be an overall focus of resources, cognition and response). Furthermore, my model needed to be able to address resilience related to overcoming the adversities experienced by the parents whose child had a tracheostomy; these elements added depth to the findings.

Overall, I wanted my model to encompass the change that occurs in individuals when stressful things happen and stress is ongoing, and when and how protective factors come into play. The risk factors for the parents in my study were multi-faceted and caused the parents cumulative stressors. Arguably, although the risk was more intense in the initial stages of their journey with their child (the parents' experiences in hospital), the risk factors accumulated and continued for them once their child was at home. Parents were more resilient when protective factors came into play, allowing them to reframe. Parents drew on specific protective factors such as their own personal resources (which were their own characteristics that supported them at certain times in their journey), such as grit. The situational resources they drew on in times of stress (both whilst their child was in hospital and when their child was at home), were supportive networks such as peer parenting support. My adaptation of Ellingsen et al.'s (2014) model with elements of McCubbin and Patterson's (1983a) work presents how risk and protective factors fluctuate over time and how the parents responded in several ways to their adversity.

The word resilience has roots in the Latin verb, *resilire* (to rebound), and one of the key aspects of the parents' resilience was a sense of elasticity that reflects the parents' ability to be stretched by situations and to reframe their lives and beliefs (Smith et al., 2008). This positive reframing could be seen in the way that the parents bounced back from the stressors they experienced. The stories told by the parents of 'going with it' and 'holding their own' essentially represent a reframing process. Overall the journey that occurred for the parents in my study allowed them to reframe (go through an ongoing process of resilience), and this reframing was evident at various levels of intensity at different time points. The parents in my study continually reframed their lives, arriving at fresh understandings as a result of their own experiences. For example, the parents reframed their perspective about a tracheostomy they did not want, to something that saved their child's life. The process of reframing will be explored further in the (X) response domain.

The domains of the ABC-X model have a strong connection to the parents' experiences and no qualitative published work has been identified that shows the application of the ABC-X Model to parents' experiences of having a child with a tracheostomy. However, Joseph et al. (2014) did apply the Double ABC-X Model of Stress and Adaptation (McCubbin & Patterson, 1983a) in a quantitative study of families that care for children with a tracheostomy, and Joseph et al.'s quantitative study provides an exploration of variables that focus on stress, coping duration of tracheostomy and quality of life. The Double ABC-X model was found to address these variables so that practitioners can support and potentially prevent predictable crisis for families with a child who has a tracheostomy. Joseph's study also had a proportion of parents whose child was on LTV, who arguably have a different clinical pathway to a child with a tracheostomy who does not require LTV (see literature review chapter). The application of my ABC-X model of parental resilience and reframing adds to this evidence base about the value of the ABC-X model, because my study has a longitudinal aspect and followed the parents' experiences over time (pre- and post-tracheostomy), with a focus on risk and protective factors. Cordon and Millar (2007) note that understanding how and why change is created lived and experienced is important to develop policy. The model I have developed supports the better understanding of how the parents faced and cared for their child with a tracheostomy over time, and how the process of resilience allowed them to reframe their lives.

The domains in my model not only provide a means of explaining the process of reframing and resilience but they also provide a pragmatic means of aiming to improve practice by allowing professionals from all health and social care backgrounds an insight into what supportive role they could play in helping parents of a child who needs a tracheostomy. Professionals can draw on this model to support parents through the shock and emotional upheaval they may experience when their child needs a tracheostomy. The model will highlight the parents' journey showing the positive outcomes that can be achieved within a resilient mindset. This study shows that resilience is central to the experiences of a parent whose child had a tracheostomy. In the next section of the discussion I will look at each of the domains of the proposed model of resilience; although I present the domains as discrete sections, it is important to note that there was inevitably some overlap between the domains.

The domains of the ABC-X model of parental resilience and reframing

The key findings of this study are presented within four domains of the ABC-X model of resilience and reframing (see Figure 7.1). These domains best describe how the parents showed resilience and reframed their lives when faced with their child needing to have a tracheostomy. Acknowledging the risk they faced and drawing upon their protective factors enabled the parents to reframe their lives and beliefs.

The four domains are:

- Domain A, Level of risk
    - Intensity of risk: (fear, uncertainty, unexpected diagnosis)
    - Accumulation of risk: (negativity, pressures, parents managing it alone)
- Domain B, Resources
    - Personal resources: (grit, gratitude, self-awareness)
    - Situational resources: (parents supporting each other, support networks.)
- Domain C, Cognition
    - Being in control
    - Feeling more positive
- Domain X, Response
    - Reframing

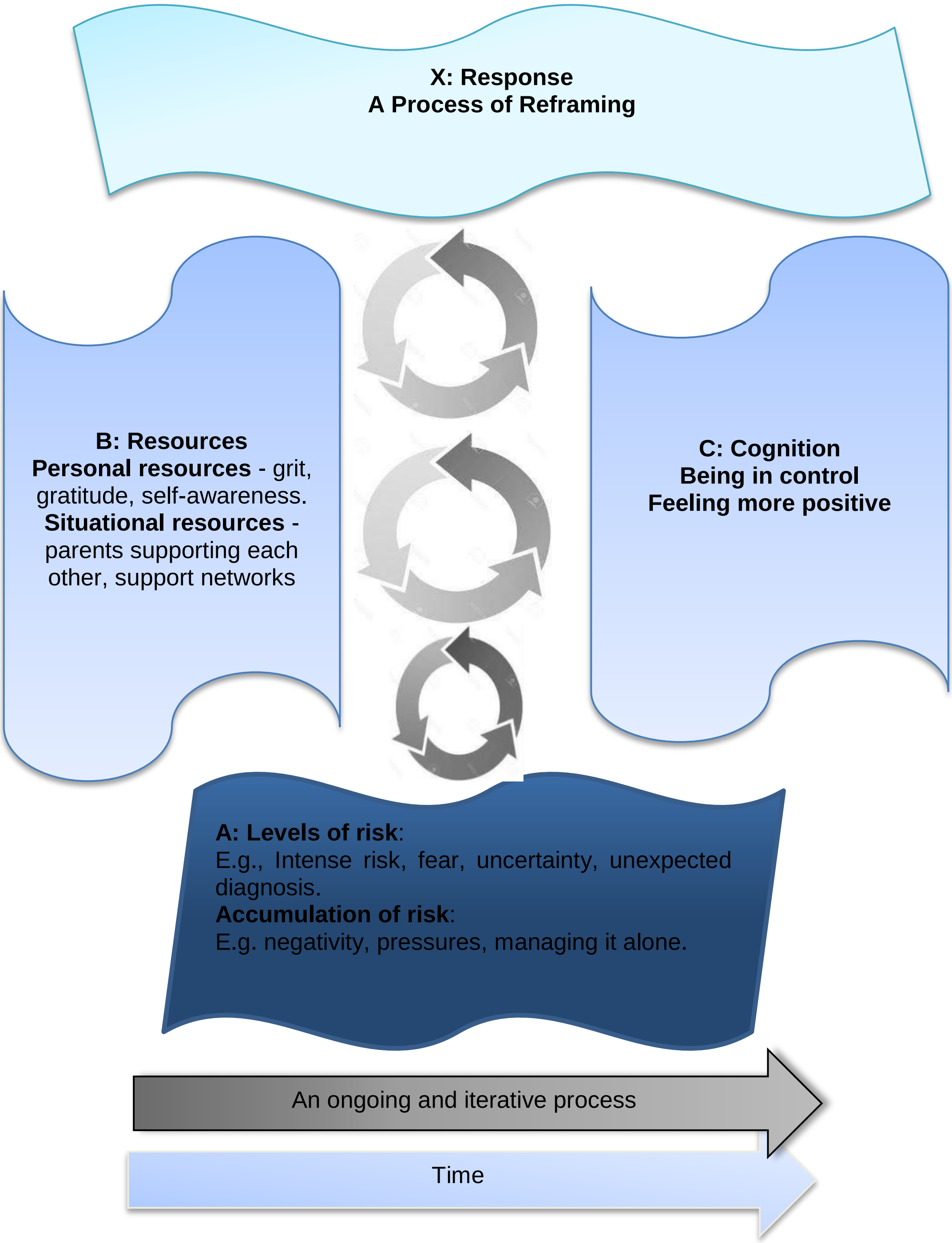


Figure 7.1: The ABC-X model of parental resilience and reframing

Typically, the sort of trajectory the parents followed was one where their level of resilience was challenged and became lower when they faced the initial adversity of their child having breathing problems and needing a tracheostomy. Following this, they then faced ongoing challenges when learning to care for their child's tracheostomy, the stress associated with taking their child home and also dealing with people's reactions to their child. The model depicts the 'Risks' associated with those challenging times at the bottom of the figure (depicted in dark blue). The model presents ‘Resources’ and ‘Cognition’ (depicted in light blue), the circular arrows between these two domains show how parents built stronger, albeit fluctuating, levels of resilience overtime. Ultimately ‘Resilience’ is presented at the top of the model, as is appropriate for the overriding domain as it was resilience allowed the parents to reframe their lives and resilience is the key finding of this study. These domains and how they reframed will now be presented in more detail in the following section.

Domain A, Level of risk

Most people experience some severe adversity in their lives which can lead them to experience ongoing stress (Bonanno, 2004). For the parents in my study the level of risk their child faced because they had breathing issues was initially intense because parents faced times of fear, uncertainty and an unexpected diagnosis. The accumulation of risks that their child faced during their first year of having a tracheostomy created considerable stress and pressure for the parents. These risks included the surgical intervention to create a tracheostomy. As the number of risks and stress increased (e.g. facing the first tracheostomy tube change and managing their child’s tracheostomy care at home,) the sense of stress and risk accumulated. In the next section, the discussion will explore how parents faced and dealt with the many risks that were associated with their child having breathing issues.

Intensity of risk

This section addresses situations of intense risk, the fear and the uncertainty associated with risk and the risk associated with diagnosis. The early experiences of their child being ill were stressful, complex and multifaceted for the parents. The high levels of risk their child faced and that the parents had to deal with were initially overwhelming, with them having no choice but to face the fact that their child might die. At times of intense risk parents’ emotions and lives were stretched to their limit. The parents had to face the challenges of their child being in intensive care, the uncertainty of what was wrong, and then receiving an unexpected diagnosis; all of these challenges were faced at a time when their child's life was at risk.

Intensity of risk: uncertainty

Parents faced times of uncertainty when trying to get the right medical help for their child and the shock of receiving a diagnosis. The immediate risk to their child's life and seeking the right medical help involved some parents being transferred from one hospital to a specialist hospital. For some parents, the uncertainty was very stressful because they reported that they were kept in the dark about their child's medical issues. Risk always existed for the parents in the context of uncertainty. The majority of parents divulged that initially they did not know what was wrong with their child and that this lasted for some considerable time. Studies have reported that parents get extremely frustrated when experiencing delays in knowing what is wrong with their child (Hummelick & Pollock, 2006), and this can cause shock (Firth, 1983) and emotional distress (Davies, Davies, & Sibert, 2003); Altiere & Von Kluge, 2009). Whiting (2014) discusses how parents of children with a disability or complex health care needs can experience delays in diagnosis and parents from his study report this as one of their most powerful concerns.

Graungaard and Skov (2006) found that parents of children who are severely disabled discussed that getting a certain diagnosis was important to them and if this did not happen it led them into an uncertain future. In the early stages of diagnosis, my parents told stories where they were rarely certain about what would happen next in relation to their child's medical problems. Parents in other studies have reported 'uncertainty' surrounding the medical state of their child with a tracheostomy (McNamara et al., 2009), or who was on LTV (Wilson et al., 1998; O'Brien, 2001; Mentro & Steward, 2002; Mah et al., 2008). Parents shared with me how they felt angry during these times of uncertainty as they said they were kept in the dark about what was wrong with their child. Parents in other studies experienced anger where a delay in diagnosis had been an issue (Young, Dixon-Woods, Findlay, & Henry, 2002; Green, 2007). Mishel (1988) emphasised that a major way to improve parents' uncertainty is that the health care team deliver appropriate and timely information. My findings suggest that some parents had assumed that their child's breathing was normal and had lived with it for some time until eventually it was clear this was not the case. This then led to the parents feeling not only uncertain about what was wrong with their child but also alarmed with how they had lived with it on a daily basis, because they had not known of the dangers.

Intensity of risk: fear

The parents in my study reported how fearful they were when finding out that their child had life-threatening breathing issues. According to Fowlie and McHaffie (2004) most expectant parents do not think about the possibility that their newborn child may be seriously ill and the most intensely stressful period of time for these parents was when they faced the risk that their child might die at birth. The parents in my study faced many emotions at this time about their child's immediate future, which was very stressful and an emotional period of time characterised by shock and distress. Bolger (1999) analysed the process of working through emotionally painful experiences in people who suffered traumatic experiences as a "brokenness of the self" characterised by four properties: a sense of being wounded and disconnected (from a loved one), loss of self, and loss of control and a sense of alarm. The early stories parents told were distressing accounts of emotionally painful experiences and like Bolger's findings my parents reported being 'broken' when they found out their child had breathing issues. Parents stories presented a sense of being wounded because things had not turned out the way they had hoped, and alarmed at what had happened to their child either because they had not anticipated or had not been as one parents describes "*made aware"* that their child would have any breathing issues. A sense of having no control over these events was expressed by the parents as feeling powerless because they were disconnected from their child at birth, and from each other. Feelings of helplessness and fear for their child's life emerged for the parents as they, for example, "*watched them*" [doctors/nurse] resuscitate their child. Not surprisingly parents in other studies have reported feelings of fear when their child needed to be resuscitated (Maxton, 2008; Harvey & Pattison, 2012). Parents in these studies who witnessed the resuscitation of their child experienced negative emotions and feelings of not being allowed by professionals to go to their child

(Harvey & Pattison, 2012); however, for some parents being there was important to them and less stressful than the possible outcome of their child dying (Maxton, 2008).

The parents' emotions changed in intensity and duration when they were fearful about their child's life and felt a lack of control. Parents mentioned the term roller-coaster ride of emotional ups and downs on several occasions in relation to their early experiences. This term represented the parents' emotions when they were fearful of the risk to their child's life and the lack of clarity about their child's future. The term roller-coaster has been used by parents in other studies to describe their emotional and ongoing experiences of dealing with their child's ill health (Foster, 2010; Gomez-Ramirez et al., 2016).

The response to their child's life being in danger continued for the parents when having to face the Intensive Care Unit. Upon admission of their child to the Intensive Care Unit parents also encountered the environment, and for some of the parents this reinforced the critical situation their child was in, and made them realise that something was seriously wrong with their child. Baia, Amorim, Silva, Kelly-Irving, De-Fretas and Alves (2016) discuss that being a parent of a pre-term baby who needs a subsequent intensive care admission are at risk of immediate and extended physical and emotional burden. Other studies have reported significant parental distress (Colville et al., 2008), shock (Noyes, 1999; Bond, Obeidat, & Callister, 2009), and anxiety and depression (Cronin, 2003; Gale, Franck, Kools, & Lynch, 2004) when their child has been admitted to an Intensive Care Unit. However, the findings from this study show that although parents did not want their child to be in the Intensive Care Unit they did express how grateful they were to the health professionals on the unit. This gratitude has also been described in other studies (Kowalski, Leef, Mackley, Spear, & Paul, 2006; Colville et al., 2008)**.** Most parents were grateful for the admission to the Intensive Care Unit because they felt hopeful that finally something might be done to resolve the risk to their child's life.

However, one of the most distressing aspects that two of the parents discussed whilst their child was receiving intensive care was their fear of not bonding with their child. Bonding is considered the central '*developmental force*' across the lifespan (Feldman, Weller, Leckman, Kuint, & Eidelman, 1999 p 929). Heermann, Wilson, and Wilhelm (2005) have reported feelings from parents of how intimidating an intensive care environment can be and how this can result in delayed maternal attachment. For one mother in my study, not being able to hold her child more than the nurses did while she was in the Intensive Care Unit added to her emotional distress. Early separation has been shown to increase strain on the infant-parent relationship, especially during long stays in intensive care, where mothers become highly anxious and emotional because there are disturbances of maternal attachment (Hall, 2005; Soderstrom, Benzein, & Saveman, 2003).

Having a baby in intensive care is an overwhelming experience and some parents in this study reported that staff would communicate everything that was going on and this was of great comfort to them when they were fearful. Fenwick (2001) proposes that chatting with parents is an important clinical tool that nurses should use to assist parents to become connected with their child. Findings from my study indicate that nurses who help parents to talk through their feelings and fears at such a risky time for their child is important and helpful. Hopia, Paavilainen and Stedt-Kurki (2005) discuss family experiences when their child is in hospital as stressful and how nurses play a key role in sharing the emotional burden.

Intensity of risk: unexpected diagnosis

Once their child had been diagnosed, the parents in my study experienced uncertainty, concern, shock and distress about what this would mean for their child's future. The acute emotional shock upon their child's diagnosis and fears for the future of their child described by the parents in my findings aligns with findings from many other studies that report that the initial shock of diagnosis is devastating (Bartolo, 2002; Sari, Baser, & Turan, 2006; Boss, Hutton, Sulpar, West, & Donohue, 2008; Nusbaum et al., 2008). Most of the babies or children in my study received a diagnosis which had more than respiratory implications and was either a named syndrome or a long-term condition and, in many cases, this was a shock to the parents. Parents felt that they had waited a long time to find out what was wrong with their child. These findings are similar to Baird, McConachie and Scrutton's (2000) study on parental perceptions of getting a diagnosis of their child's cerebral palsy; the authors discuss a protracted and complex process of confirming and disclosing a diagnosis.

However, not all parents react in the same way, and Faerstein (1996) noted that mothers acted objectively and their reaction to their child's diagnosis led to relief rather than shock because it ended their distress of uncertainty. Findings from my study show that shock and worry about the risk to their child's life carried on for the parents**.** Even after learning about their child's diagnosis there was no time to digest the information that they had been given, and many parents discussed that the amount of medical information they received was overwhelming and they felt a sense of helplessness. These findings are in line with other studies that report parents feeling overwhelmed by their child's diagnosis (Lowes, Gregory & Lyne, 2005; Sari et al., 2006).

Parents found themselves in unknown territory with a sense of feeling helpless and out of control, and uncertain what the risk was for their child; these feelings have been discussed in other studies (Hummelick & Pollock, 2006; Bartolo, 2001). Shock seemed to be a precipitating factor which drove some parents to search on the internet for information and answers. The ability to seek this information on the internet is a modern-day occurrence. Research has documented the key role of the internet in enhancing patient self-advocacy in routine healthcare encounters and when confronting rare or contested illnesses (Barker, 2008; Gundersen, 2011; Schaffer, Kuczynski, & Skinner, 2008). O'Connor and Madge (2004) propose that parents seek information on the internet to confirm information already given by the doctor, to get a second opinion or to confirm what they are thinking. However, many studies have reported that health-related information available to parents on the internet can be misleading and occasionally wrong (Pandolfini, Impicciatore, & Bonati, 2000; Eysenbach, Powell, Kuss, & Sa, 2002). Gage and Panagakis (2012) discuss how parents of a child who had been recently diagnosed with cancer found the internet to be untrustworthy and frightening, and some avoided seeking information due to fear of what they might find out. Findings from my study suggest that parents who explored the internet about their child's condition terrified themselves. However, parents found comfort in talking through the information they had found with health care professionals who could provide reassurance and clarity. Williamson, Creswell, Butler, Christine, and Halligan (2016) also report that parents prefer talking with doctors and saw this as more useful than the internet. Furthermore, Gage and Panagakis (2012) found that throughout the acute crisis of a child being diagnosed with cancer, parents preferred to receive information related to their child's diagnosis and treatment options from a trusted healthcare provider instead of the internet.

Conclusion to intensity risk

This section of the discussion has explored parental fear and uncertainty because of the intense risks to their child. At the time of risk to their child's life, parents had to respond to their child being in the Intensive Care Unit, getting a diagnosis, and the shock and emotional upheaval caused by the medical information they received. Dealing with all of these issues was a struggle for the parents and they expressed their fears for the future for themselves and their child's life**.** The next section will explore how the sense of risk accumulated which impacted on the parents as they struggled with the realization that their child needed a tracheostomy.

Accumulation of risk

The intense risks associated with their child's breathing issues resulted in an accumulation of risk and stressors regarding the challenges of facing surgery to perform a tracheostomy for their child and managing their child with a tracheostomy at home. Although these risks were less intense parents were still challenged. Rutter (1979) proposes that when two or more risk factors accumulate in a person's life the probability of an individual being less able to cope with the stressful situation is significantly bolstered. McCubbin and Patterson (1983a) discuss how stressors can affect each family member, and these can overlap and sometimes multiple crises can occur at the same time.

Accumulation of risk: negativity

My findings suggest that the parents faced an accumulation of risks and stressors during the course of their child's first year of requiring a tracheostomy. A key factor influencing the parents' struggle and ability to make decisions was their negative reaction and emotions towards their child needing a tracheostomy. Given the severity of their child's breathing issues the only option for the parents was for their child to have a tracheostomy and, as Srivastava, Stone and Murphy (2005) note, this lack of options is not unusual for children with complex breathing issues.

The need for their child to have a tracheostomy had to be faced by the parents because their child's breathing issues would not resolve. The findings of my study show that many parents thought that their child needing a tracheostomy was unfair and perceived this to be "*the end of the world*" for them and their child. Parents emphasised their fears about their child having a tracheostomy and some initially resisted the need for the tracheostomy. The mention of their child needing a tracheostomy was shocking, and one father reported that at the time of a tracheostomy being suggested he felt he was having a breakdown. No other study has been identified that has reported parents' initial reactions to the mention of a tracheostomy being needed for their child. However, there is clearly a need for greater support for parents in terms of their well-being during this and other critical time periods. So, although the child's needs are inevitable, and are going to take precedence, parental well-being should also be high priority in family-centred care (Franck & Callery, 2004).

Accumulation of risk: pressures

One of the most significant challenges faced by the parents in my study was making the major, life-altering decision for their child to have a tracheostomy. The only option to reduce the risk to their child's life was to have formation of a tracheostomy. Stewart, Kimberly, Pyke-Grimm, and Kelly's (2012) study on parents whose child has cancer note that making the right decision for their child was emotional and challenging, but concluded that decision-making was an extension of the parental obligation to act in the child's best interests. Like the parents in Stewart's study, my parents perceived the decision about a tracheostomy as emotionally difficult but they had no other choice; this left them feeling fearful and distressed. Carnevale et al., (2006) discuss that parents found making a choice about life-support decisions for their child was not a true choice, as when the alternative is to let your child die, "free choice" is really a virtual choice. This view is in line with the findings from this study, as my parents felt that they really did not have a choice apart from to accept a tracheostomy for their child.

The findings of this study suggest that parents had preconceived views about tracheostomies which put pressure on them because they felt it would impact on their child and their lives in a negative way. Other studies show that parents are reluctant for many reasons to accept a diagnosis or complication resulting from a life-threatening illness for their child (Giannini et al., 2008). Oandasan and Reeves (2005) propose that collaboration among various health professionals and their patients with shared decision-making about their health care is a logical and coherent way to integrate the engagement of patients as partners. Most of the parents in my study, through discussion with the consultant and health care team eventually came to accept that the risk to their child’s life was high and their child having a tracheostomy was their only option. However, some parents realised the need for a tracheostomy before the doctors, and brought the subject up themselves. Even though many parents did not want a tracheostomy, they could not tolerate to see their child suffer anymore.

Preparing for their child’s surgery and going to theatre posed high risks for their child which impacted on parental well-being, making them stressed. Parents recalled feelings of distress and sadness about the day their child had surgery, and these emotional responses have been reported from parents in another study (Klein, Pope, Getahun, & Thompson, 2006). A sense of powerlessness, lack of control and emotion were reported by the parents in my study prior to their child going to theatre; these feelings have been reported by parents in other studies when their child faced surgery (Daniel, Kent, Binney, & Pagdin, 2005; Sanders, Carter, & Goodacre, 2008; Solveig, Marit, & Judith, 2009). Some parents discussed the day of their child’s operation as “*horrible*” and the waiting around as difficult for them. Other parents expressed relief that finally something was being done to alleviate their child's breathing issues.

Parents recalled the use of "*the death word*" when they were faced with the implications and major risks of their child's surgery, and when signing the consent form for their child's operation. The critical nature and risks of surgery made parents realise just what was at stake. Signing the consent form with the knowledge of the surgical risks and that their child might not survive was emotionally distressing for the parents. Previous literature reveals parents' experiences of intense distress and feelings of helplessness when signing consent for their child's surgery (Kain, Caldwell, & Wand, 2002; Pfeil, 2011).

Some parents reported they felt shocked and negative about their child's appearance when they saw their child with a tracheostomy for the first time, and it took time for them to reframe. In contrast, other parents reframed immediately as they saw an instant improvement in their child's breathing with the tracheostomy. Bonanno (2005) notes that people have individual pathways of resilience, with some developing negative reactions to a crisis and others adapting to their adversity more easily. The parents' pathways over the first year of their child having a tracheostomy were not all the same and some took longer to reframe. This further resonates with Bonanno (2004) who discusses that there are multiple and unexpected pathways to resilience.

Accumulation of risk: parents managing it alone

The ongoing sense of risk remained and this was reflected in the stories the parents told of preparing for going home with their child; these stories were often full of anxiety and uncertainty about being able to undertake their child's care. Caicedo (2015) also reported that parents can become anxious because of the challenges of looking after their child with complex needs at home. The parents in my study told stories about how they felt that going home was a "*double-edged sword"*. They were happy to be going home, but scared and worried about their ability to care for their child; these fears continued for the first weeks at home**.** Parents of children with congenital heart disease have also reported the weeks following discharge from hospital as particularly difficult because there is a sudden change in the 24-hour supervision and support that they had received in hospital (McCrossan, Grant, Craig, & Casey, 2007). Health issues such as abnormal heart rhythms, cyanosis, chest infections and psychological trauma may be significant problems for the rest of these children's lives. These complications are most acute in the months following initial discharge from hospital in infancy (McCrossan et al., 2007). The problem of going home for parents in my study related specifically to leaving the support of the hospital but also involved caring for their child at night time, worries about their child getting into difficulties, and fear about having to resuscitate them.

The findings from the parents in my study resonate with the findings from studies of other parents caring for a child with a tracheostomy, who also report constant worry about their ability to manage their child's care successfully (Montagnino & Mauricio, 2004; McNamara et al., 2008). Some parents discussed with me how anxious and challenged they felt about doing their first tube change at home and for some it took a while to get used to doing this procedure. Other parents of children who have a tracheostomy have reported their feelings upon changing their child's tracheostomy tube as "*scary*"; they also were fearful of hurting their child (Montagnino & Mauricio, 2004), and seeing their child in distress caused them feelings of guilt (Kirk et al., 2005).

Parents reported feeling that their role was not considered enough by nurses, who tended to see them as carers not parents, which has also been seen in other studies (Reeves et al., 2006). Other studies have also reported issues related to insufficiently considering parents' feelings. These studies found that services in the community were not sufficiently developed to support families at home (Kirk & Glendinning, 2004) and there were barriers to negotiation of care between nurses and parents (Kirk, 2001). Parents of children with tracheostomies discuss the central role they are required to play in response to the lack of or poor operationalisation of care packages (McNamara et al., 2009). It is well documented that a lack of collaboration between services and issues of parental support is an ongoing problem (Ludvigsen & Morrison, 2003; Noyes, 2002; Jardine, O'Toole, & Wallis, 1999; Stephens, 2005). Kirk's (2001) study about the negotiation of care for children with complex health care needs found that professional expectations of parental involvement in the care of a sick child can act as a barrier to the negotiation of roles and parents’ feeling constrained by their obligation to their child. Findings from my study suggest that some parents found it challenging to get the right care for their child with a tracheostomy. Reeves et al. (2006) reported that parents wished for more confident nurses to help care for their child. The continued strain for parents in my study from negotiating the right type of care, and simultaneously maintaining control over it, was difficult and stressful for them. Despite the fact that there has been policy guidance for many years on continuing care (DH, 2003; DH 2004; DH 2006; DH 2007; DH 2009; DH, 2010), it was clear that parents were struggling to get the right care to support them and their child at home. This suggests that despite the existence of policy aiming to support continuing care, the reality is that it is being inadequately implemented, leaving parents without appropriate support. The most recent guidance document, the *National Framework for Children and Young People’s Continuing Care* (2016), offers little new in terms of real change and support, meaning that the future for children requiring continuing care is likely to remain unchanged in terms of support for parents.

Some parents reported feeling upset because they and their child were “*stared at*”, or they felt other people reacted badly to them carrying out their child’s tracheostomy cares whilst in public places. However, some parents told stories of how they challenged people who had expressed sorrow because their child needed a tracheostomy. Parents in my study reframed their beliefs about a tracheostomy and were happy to voice to people that it had saved their child’s life. Research has reported the challenges that parents’ may face in managing other people’s reactions to their child’s condition, such as their child having a tracheostomy (Mah et al., 2008), or complex health care needs (Kirk & Glendinning, 2004; Rehm & Bradley, 2005; Woodgate et al., 2012). Protecting their child from unwanted attention and sympathy was important to the parents in my study. Parents expressed that when people showed a positive interest in their child they were happy to explain why a tracheostomy had been needed.

Some parents also discussed a lack of understanding from family members about their child who had a tracheostomy. Parents often felt a need to confront family members about their feelings about their child's tracheostomy. Parents wanted their child to be treated as normal and live as normal life as possible. This is consistent with other studies which have explored what constitutes a normal life for children on long term ventilation (Ganntt, 2002; Carnevale et al., 2006; Rehm & Bradley, 2005). Normalisation is represented as a positive attempt by parents to incorporate their child's disability/complex needs into day-to-day family life (Rehm & Bradley, 2005). Findings from my study identified the challenges the parents faced in wanting their lives to be normal, and their child to be treated no differently to their other children. Previous research has suggested that parents of children with cancer are able to construct a new sense of normality despite the uncertainties of the future (Stewart, Kimberly, Pyke-Grimm, & Kelly, 2012). My findings suggest that parents are able to reframe their beliefs and lives and create a sense of normality, even if it was a challenge to them.

Conclusion to accumulation of risk

In conclusion, my findings relating to accumulation of risk show that the parents displayed negative emotions towards a tracheostomy but eventually accepted that their child would only survive if they had a tracheostomy. Parents then faced numerous pressures (such as the day of surgery, the first tracheostomy tube change, going home for the first time with their child and facing the reactions of others to their child) and were challenged to manage these pressures. At this time point parents were under increased stress and anxiety which impacted on them, and the next domain will start to explore the protective factors that the parents drew upon to conquer these challenges and develop resilience.

Domain B, Personal and Situational Resources

This domain considers the personal and situational resources that the parents drew upon when their child needed a tracheostomy. Protective factors have been described as being able to buffer, intercept or even prevent risk (Masten, 1994; Werner & Smith, 1982). Resources were protective factors that moderated the effects of risk for the parents in my study. Cowley (1995) discusses the multiple interacting influences of resources and that it is essential to view each combination as unique to both the individual and the circumstances in which that person is living.

Personal resources

Grit and gratitude were characteristics the parents utilised in response to facing and accepting a tracheostomy for their child. Grit is emotional strength involving the pursuit of long-term goals with perseverance and passion (Duckworth, Peterson, Matthews, & Kelly, 2007). Grit was a protective factor that helped parents to face adversity and it allowed them to make progress to reframe. Gratitude was an appreciation about the positive changes that the tracheostomy brought to their child's life. In understanding how people face adversity it is undoubtedly important to identify the characteristics such as grit and gratitude that may promote resilience**.** When grit and gratitude are present together they have been described as having synergistic benefits as protective factors (Kleiman, Adams, Kashdan, & Riskind, 2013). Self-awareness was another characteristic displayed by parents and it has been described as a key factor of resilience that individuals look for within themselves for a better understanding of their thoughts, beliefs and emotions (Hippe, 2004). The discussion in this domain focuses on grit, gratitude and self-awareness in more detail, and explores the personal resources that the parents drew upon to achieve a resilient mindset and reframe their lives

Personal resources: grit

At each stage of their journey the parents showed a gritty determination to conquer obstacles. Fosha (2002, p2) highlights that "trauma awakens" extraordinary capacity in people that they might not have otherwise exhibited. Personal protective factors have been described in the resilience literature as ever-present and facilitate adaptation to stress (Garmezy, 1991). Parents were courageous and resolute in their determination to overcome the challenges they faced and to strive towards the long-term goal of getting home with their child despite setbacks and challenges. My findings revealed that parents faced some tough situations when learning to care for their child's tracheostomy. Changing the tracheostomy tube for the first time was a particular challenge for some parents who knew they had to achieve this so that they could go home. Success in changing the tracheostomy tube was not just a technical skill for the parents and required grit, spirit and a commitment to overcome their anxiety of performing a task their child's life depended on. High levels of grit are seen as of particular value in achieving success when the task is difficult (MacNamara, Hambrick, & Oswald, 2014). The parents in my study demonstrated high levels of grit, determination and extraordinary resilience in being able to overcome their fear of changing their child's tracheostomy tube. A meta-synthesis of research on resilience in the older adult population concluded that grit was one of the protective factors that older adults drew upon in their everyday lives to keep going (Bolton, Praetorius, & Smith-Osbourne, 2016). My findings suggest grit was also a protective factor in parents' everyday lives and that this characteristic helped them face their fears move forward, and in some situations reframe.

Personal resources: gratitude

Parents demonstrated a degree of gratitude following formation of the tracheostomy. The concept of gratitude has been debated in the literature, as to whether it is a personality characteristic or an emotional state, although the overall sense is that it can be a characteristic, a mood or emotion (McCullough, Tsang, & Emmons, 2004). My findings suggest that parents were grateful for a tracheostomy because it saved their child's life. Woods, Maltby, Stewart, Linley, and Joseph (2008) note that gratitude has been viewed as a characteristic that appreciates the positive in the world. Despite various emotions that the parents experienced throughout the first year of their child having a tracheostomy, gratitude was a key characteristic that allowed them to eventually see the positive and reduce any negative feelings they had previously experienced. Parents discussed how the tracheostomy had brought their lives into perspective and they could now move forward towards a future with their child.

Watkins (2004) proposes that gratitude may be characterised as recognising the gratuitousness of the gift; the more individuals value that gift the more gratitude they tend to experience. Parents in my study valued the gift of having their child alive. Gratitude can offer a new viewpoint to heal after stressful times (Watkins, 2004), and being able to be grateful for the tracheostomy served as a positive turning point for the parents' journey in my study. Turning points represent times when adversity alters direction, such as when a professional intervention enables a family to start on a positive pathway (Gilligan, 2001; Schofield, 2001). The realisation of gratitude created a sense of personal well-being for the parents; the reframing of their beliefs meant they could incorporate a unique, previously unfamiliar and unwelcome perspective (their child needing a tracheostomy) into their lives. Other studies have indicated a relationship between reframing and gratitude (Woods, Joseph & Linley, 2007; Woods, et al., 2008). Woods et al.'s (2007, 2008) work associates gratitude with making positive attributions (positive reinterpretations) and growth which in turn are related to reframing. It was evident in my study that by parents being grateful they were able to positively reframe their situation.

Personal resources: self-awareness

Self-awareness played a significant role as a protective factor for the parents when their child's life was threatened and a tracheostomy was the only option for them. Self-awareness has been discussed as the ability to recognise and acknowledge one's strengths as well as one's areas of challenges and is an antecedent to resilience (Hippe, 2004). Depape, Hakim-Larson, Voelker, Stewart, and Jackson (2006) propose that awareness of self relates to emotional intelligence and the regulation of emotions. The parents in my study had to accept their current reality and find the courage to move forward for their child. My findings suggest that parents regulated and modified their negative feelings about a tracheostomy as they could no longer bear to see their child's continual suffering. Haugstvedt, Graff-Iversen, Khan-Bukholm, Haugli, and Hallberg (2013) explored the processes of self-understanding for parents whose child had a disability and concluded that for the parents in their study self-awareness alongside reflection were crucial factors that enhanced their values. These findings about self-awareness and reflection are similar to the findings in my study because the parents became mindfully aware of what was at stake, and the only thing that could alleviate their child's struggle was a tracheostomy.

Parents openly discussed their reservations to a tracheostomy for their child and a key objection was the stigma of a tracheostomy. However, reflecting on these reservations parents became self-aware about their negative feelings of the appearance of a tracheostomy and how these reservations had been misplaced. As Silva and O'Brien (2004) note, self-awareness is linked to a person's ability to self-monitor and change their current behaviour and thought processes and it largely depends on their capacity to objectively examine the self. Over time parents told stories that reflected their different feelings about their child having a tracheostomy and living with this every day. Having to accept a tracheostomy as the only option for their child's survival allowed the parents to step back and examine their previously held beliefs. Self-awareness was most evident in my study at the time when the parents were having to face up to the critical life-and-death situation their child was in, and having to accept a tracheostomy as the only option left to save their child's life.

Conclusion to personal resources

To summarise, grit, self-awareness and gratitude were the personal resources that the parents drew upon as protective factors to overcome their adversity. The evidence presented has shown that each personal resource was an important attribute which allowed the parents to face accepting and caring for their child's tracheostomy. The parents actively sought to overcome their own beliefs and emotions about their child having a tracheostomy. The next section of the discussion chapter considers situational resources and how parents sourced support from family, health professionals and social media.

Situational resources

Parents of a child who had a tracheostomy drew upon specific situational resources as protective factors. Protective factors helped parents' deal with the stress of their child having a tracheostomy, and this helped them to find ways to reframe their lives and build and sustain trusting relationships. Resilience is built not by avoiding stress but by facing it "at a time and in a way, which allows self-confidence and competence to increase" (Rutter, 1985, p608). These situational resources included parents being able to draw on support networks such as other parents, extended family and online sources of support. When these situational resources were in place these enabled the parents to reframe their lives. The next section will explore these situational resources in more detail.

Situational resources: parents supporting each other

Parents in my study experienced many emotional events and they shared stories of how their everyday routines had changed now that their child had a tracheostomy. What was important to the parents in my study was how they worked together to support each other and maintained routines which impacted on their ability to manage their child's clinical care. However, several studies have focused on the burden parents' face when dealing with the impact of their child's tracheostomy (Harnick et al., 2003; Hopkins et al., 2009; Joseph et al., 2014). Joseph et al.'s (2014) recent study on parents' quality of life when caring for an infant/toddler at home with a tracheostomy concluded that the parents were in moderate distress. Coffey (2006) found that parents whose children have a chronic illness have reported many challenges in managing their child's care and fitting it in to a normal family routine. The parents in my study found teamwork, developing trust with each other and establishing a routine helped and supported them. This new routine required the parents to work together to keep each other refreshed and rested.

In times that were less stressful, some parents reported involving siblings as part of the tracheostomy routine. Studies about parents who care for children who are medically fragile have also discussed the importance of involving siblings and extended family members in the child's normal routine (Mentro & Steward, 2002; Mah et al., 2008). Woodgate et al. (2016) discuss that participation of siblings with a child who has complex needs should always be done mindfully and with the family needs at the forefront. My findings suggest that parents actively engaged in establishing tracheostomy care as part of the family's normal routine. Overall, parents supporting each other to establish normal family routines that included their child's clinical care allowed for an evolving process of resilience.

Situational resources: support networks.

Support networks were an important source of comfort and help to parents. These networks were composed of extended family, health professionals and online sources of support. Close supportive relationships are factors reported as being capable of fostering resilience and protecting individuals from adversity (Bonanno, 2004; Masten, 2001). The support given to parents by their extended family was discussed as a valuable resource. Knowing that family members were keen to get involved and in some cases train to help with their child’s clinical care was helpful to parents in their everyday lives.

There is an abundance of research into how parents feel about a lack of support from health professionals (O’Brien, 2001; Kirk & Glendinning, 2004, McNamara et al., 2008; Reeves et al., 2006; Hobson & Noyes, 2011; Tomment, 2003; Mah et al., 2008; Brett, 2004; Montagnino & Maurio, 2004; Mendes, 2013). However, parents in my study spoke of community health professionals being an invaluable source of support to them. It was important to the parents that community staff took the time to support them and listen to them. Parents valued the opportunity to talk openly with health professionals about their emotions or how they were getting on with life. Rutter (1987) discusses that resilience is conceived as an end product of a buffering process that does not eliminate risks and stress but that allows the individual to deal with them effectively. My findings suggest that occurrences such as talking with health professionals helped the parents deal more effectively not only with daily stressful life events but their feelings about managing and caring for a child with a tracheostomy.

Social media and the support of other parents via online groups formed another part of the parents’ support networks. Parents valued and discussed how important it was to draw upon the experiences of other parents whose child had a tracheostomy. Reassurance and empathy were important aspects of what this resource brought to parents in my study. Parents actively encouraged other parents whose child may need a tracheostomy to access these resources. This engagement with online support is not surprising as studies show that individuals increasingly rely on online social media to communicate and share information, as online communities allow for the elimination of time and geographical restrictions and allow for people to acquire information and connect with one another (Kietzmann, Hermkens, McCarthy, & Silvestre 2011; Mangold & Foulds, 2009). Parents of children with special health care needs have received particular benefits such as increased knowledge, skills and support from peer-online support groups (Kingsnorth, Gall, Beayni, & Rigby, 2011), and Thoren, Metze, Buhrer, and Garten (2013) found that parents of pre-term babies found Facebook groups were important for information sharing and interpersonal support. However, Thoren et al. (2013) also note that further research is warranted to understand what motivates online communication among parents. Motivation to use social media for the parents in my study involved the comfort of knowing and learning how other parents of a child with a tracheostomy or people with a tracheostomy manage their everyday lives. My study found that social media was a valuable and comforting resource that unified a group of people who had never met but who were continually learning from each other.

Conclusion to situational resources

Resources and support for the parents in my study came from each other and from members of their close and extended family, health professionals and people they engaged with via social media. These resources acted as important protective factors and the support they gained increased parents' resilience. In terms of parents navigating their way through problems or just living in the everyday, these resources and the support they gave each other and received were invaluable to them. In the next domain, the discussion will show the processes parents went through to acquire knowledge and control of their lives and how they understood that the 'every day' was a blessing.

Domain C, Cognition

The parents' reflections on their journey were composed of the mental processes they experienced once their child had a tracheostomy and how they viewed the journey of their child needing a tracheostomy. This section on cognition will highlight how the parents took control of their lives and started to think positively. The field of resilience has seen a progress in human strengths, wellnessenhancement and growth (Calhoun & Tedeschi, 1998, 1999; Tedeschi & Calhoun, 2004) and the development of competence (Masten, 2001) when challenged with adversity. The parents in this study were sometimes stretched to the limit but they found the strength to bounce back from adversity, be positive and reframe their lives so that their lives became less stressful and they became more optimistic. This section of the discussion looks in more detail at how the parents gained a sense of control in their everyday lives and how this contributed to them building resilience.

Cognition: Being in control

The findings from this study suggest that parents of a child with a tracheostomy eventually regain a sense of control in their lives. Following the risks, shock and upset of their child needing a tracheostomy the parents faced challenges in gaining control of their child's care in a way that they had never imagined. The parents in my study displayed what Buddlelmeyer and Powthaee (2016) discuss as a strong internal locus of control which can help individuals buffer the effect of negative experiences and external factors that were initially out of their control. These authors propose that there is a distinction made between a person's internal locus of control (where much of what occurs stems from one's actions), and their external locus of control (external factors beyond one's control such as unpredictability, fate or luck). Initially, the parents had limited control (as discussed in the section on levels of risk) due to the external forces that dictated that their child needed a tracheostomy. Parents questioned why it was their child who needed a tracheostomy, or indeed why any child should suffer in this way.

However, once a tracheostomy had been performed the parents strove to gain control through their own actions (increasing their internal locus of control). For example, one father gained control over his son's day-to-day care demands by actively choosing to take a career break. Arguably, giving up financial income could be considered a risk although this was not how this was perceived by this father. This father's action resonates with research by Ng et al. (2006) who note that individuals with an internal locus of control actively seek solutions rather than trusting solely on emotional support. Salamanca, Grip, Fourage and Montizaan

(2013) state that individuals with higher levels of internal locus of control tend to take more risks than people with external locus of control. However, Rutter (1989) discusses that such expectancies may be oversimplified because these occurrences of control can occur along a gradient. Buddelmeyer and Powdthaee (2016) discuss that an important property of internal locus of control is grit in the face of adversity, which was one of the personal resources that emerged from the findings of this study.

Once a tracheostomy had been performed, parents had to master the core skills to care for their child’s tracheostomy and initially this was a challenge for them. The experience of facing and overcoming difficulties can also promote benefits in the form of a greater propensity for resilience when dealing with subsequent stressful situations (Seery, 2011). Once parents had acquired the clinical skills to care for their child an overall sense of control came back to their everyday lives. In order to be strong and face the challenges ahead parents needed to develop competence or mastery. Parents took control emotionally and intellectually and mastered the many transitions and challenges of having a child with a tracheostomy; this was a dynamic and evolving process and it helped them to become resilient. Gaining control of the clinical care differed, with some of the parents becoming more confident than others. However, overall what was once a challenge to the parents of learning and managing the clinical care of their child’s tracheostomy became part of their everyday lives. Seery (2011) discusses the importance of gaining control and mastery as two important resilience factors in overcoming stress and adversity and hence in becoming resilient. It is clear that good training in relation to the practical, technological and clinical aspects of caring for their child promoted parents’ confidence and competence in managing their child’s care. However, transition from hospital to home felt precarious for the parents and at this time was no government-driven policy to support this transition.

Nearly all of the mothers in my study were their child’s primary carer, with the father’s role being the main wage earner. A study by Pelchat, Lefebvre, and Perreault (2003) on parenting a child with a disability also found that fathers were more attuned to the outer world, and the actual day-to-day tasks related to their child's care were not perceived by them to be their priority. The mothers in my study talked freely about how their lives had changed since their child had a tracheostomy and they had given up work, although some found it hard to relinquish their caring role when fathers wanted to get involved in their child's tracheostomy care. Other studies have reported that mothers assume responsibility for most of the physical and health care related tasks of children with complex needs (Wilson et al., 1998; Craig & Bittman, 2008; Craig & Mullan, 2010). However, as previously discussed, some of the parents in my study shared the care-giving role. Brandon (2007) discusses the benefits of two parents working together in the caregiving role of a child with complex needs and notes that the support this gives parents as invaluable. In the next section, the discussion focuses on how the parents moved forward and positivity came into play.

Cognition: feeling more positive

When seeing a difference in their child breathing issues following a tracheostomy parents allowed themselves to evaluate their negative emotions. By considering their past negative feelings they were able to feel more positive, and this positivity was part of each parent's individual ability to achieve a resilient mindset. Bonanno (2004) proposes that the central element of a resilient mindset is perception, and this was evident in the parents in my study over the first year of their child needing a tracheostomy, where their feelings towards their child's tracheostomy did change. However, Lazarus (2003) states that it is difficult for individuals to produce a change in their feelings from negative to positive, although if individuals engage in positive thinking and abandon their past stressful experiences they can find well-being in their lives. My study gathered evidence from parents that spoke of the difference the tracheostomy had made to their child's life, and seeing their child happy made them more positive about a tracheostomy. Some parents talked about how a tracheostomy had put life into perspective and that the tracheostomy had not been as awful as they had anticipated.

Positive emotions help individuals to flourish and experience positive emotions such as joy, contentment and love; these positive moments are when individuals are not plagued by negative emotions such as sadness or anger (Fredrickson, 2001). This is consistent with Fredrickson, Tugade, Waugh, and Larkin's (2003) view that positive emotions are a critical ingredient in developing resilience and fuelling thriving. The parents in my study had more optimistic views of the future once they could see an improvement in their child's breathing issues as a result of a tracheostomy. Parents became optimistic as their child thrived; they explained that after the tracheostomy had been performed they believed that their child would experience good future outcomes.

Studies show that when parents have positive expectations for the future they experience less anxiety (LaMontagne, Hepworth, Salisbury, & Riley, 2003; Trunzo & Pinto, 2003), more positive emotions (Lai et al., 2005) and they have more life satisfaction (Bailey, Eng, Frisch, & Snyder, 2007; Leung, Moneta, & McBride-Chang, 2005). One of the reasons why some of the parents in my study were optimistic about the future was that they hoped the tracheostomy was not going to be a permanent feature in their child's life. This thought of a future without needing a tracheostomy made the parents feel hopeful. However, the parents became content with managing their child's tracheostomy because they knew it had helped their child to survive, and their optimism even included a future where their child still needed a tracheostomy. The thing that mattered most to them was having their child survive and be with them.

According to Seligman (2002), building a sense of optimism is essential to forging a life that is not merely happy but which is meaningful as well. My findings suggest that parents had made it their mission to make their child's life meaningful and to give them the same opportunities as any other child. Socialising by going to play at nursery or playgroups was an activity that the parents wanted in their child's life. Parents felt play was essential to their child's development because it contributed to their physical, social, and emotional well-being. The enterprise of cultivating an optimistic attitude towards a normal social life for their child helped develop a sense of themselves as parents, giving them hope for the future and a greater sense of well-being for their child. Novick and Novick (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. The parents in my study exercised their emotional muscles and adopted an optimistic view about seeing their child not only happy but also having a meaningful life; this in turn promoted their own resilience.

Conclusion to cognition

Over the first year of their child needing a tracheostomy, parents' initial negative feelings about a tracheostomy transformed into more positive feelings. Positive emotions displayed by the parents led to higher levels of resilience. Parents focused on how they could take control of their lives and put steps in place towards their future. Succeeding in mastering the clinical skills of caring for their child's tracheostomy brought some control back to the parents, especially to the mothers when caring for their child. The next section of the discussion focuses on how the overarching concept of resilience in my study was evident in the way the parents reframed their lives.

Domain X, Reframing

My findings demonstrated that parents went through a process of reframing that allowed them to develop a new sense of themselves as parents of a child who had a tracheostomy. This section of the discussion will explore how reframing was triggered by overcoming adversity (e.g., their child's illness, diagnosis, need for surgery and the subsequent challenges they had to face relating to their child's respiratory management of a tracheostomy), and becoming more able to deal with the risks associated with their child's health care needs. Reframing involved parents building a different life now that their child had a tracheostomy. Kirmayer, Sehdev, Whitley, Dandeneau and Isaac (2010) propose that recovery from adversity does not always involve returning to how life was before adversity but to a new formation that fits the different life or environment. This section also focuses on how, as time progressed and the parents became more experienced and confident in caring for their child in this different environment, they could 'bounce back' from challenges and become stronger as a result.

Although other researchers have used the terms coping and adapting to support the concept of resilience, I have chosen to use the term reframing. Initially, when reviewing the literature and the findings of my study I could have presented the discussion in terms of stress, coping and adaptation, as these concepts are clearly evident within my findings. Most of the literature on resilience has been undertaken using a psychological lens and this perhaps explains the continued focused on the key psychological concepts of stress, coping and adaption (see for example, Masten, 2001; Walsh, 2003; Folkman & Moskowitz, 2004; Delongis & Holzman, 2005; Adger, 2010: Bitsika et al., 2013; Moraz, 2015). However, the concepts of coping and adaptation in particular seemed to me to be terms that did not fully express the parents' responses to stress. Stress was a risk factor faced by the parents and stressful situations were an ongoing process for them throughout their journey. The stress the parents experienced is evident in the findings and discussion chapters (in particular in the early stories, see chapter 5 findings, p121) and it is also clear how and when parents draw upon their resources and protective factors to help them to reduce their stress (see, chapter 5 findings, p182). The terms coping and adaption seemed to me to be somewhat negative terms that inadequately reflected the positivity and growth of what I witnessed. Another reason for moving away from these terms was that I felt that they had negative connotations in that they are sometimes seen in terms of being binary: coping or not coping and adapting or not adapting, with the suggestion that the parents are at fault if they are not coping or not adapting. Although it could be argued that my choice of the word reframing is simply a different term to encompass the process of adaptation (and thus the process of coping), it was important to me to use the term reframing which is a more positive, contemporary and affirmative term to describe the processes that the parents went through. Other writers have also used the term to describe the process of growth and change (Gordon, 2008: Lambert, Graham, Fincham, & Stillman, 2009; Samios & Baran, 2018; Booth, 2015).

Reframing is at the heart of resilience because individuals have the power to reframe their life narrative (Wolin & Wolin, 1993). Booth (2015) discussed reframing as a coping strategy which can foster positive growth that in turn helps foster resilience. The choice of reframing allowed me to consider and potentially forefront how parents managed to bounce back from their situations of adversity.

As the parents became accustomed to situations that challenged their perceptions (such as their child needing a tracheostomy) they reframed their views and were able to move on. The notion of reframing capitalises on the positive nature of the parents’ responses to adversity and the positive themes within their stories, for example how they discovered that a tracheostomy was not the ‘end of the world’ for them or their child. Reframing was the process by which parents changed the ‘frame’, through which they viewed their circumstances.

Lakoff (2004) claims that individuals look at issues through frames which act as a deep mental structure shaping the way they see the world, and Thorpe (2012) proposes, more simply, that reframing involves changing the way people see things. When reframing has occurred, both emotional and behavioural changes follow, helping people to further manage and resolve the stress (Madden-Derdich, & Herog, 2005). Inherent within the structure of reframing in this study, is the belief that the parents had the resources they needed to make the desired change and redefine their negative situation into a positive one.

This study showed that the parents came to realise that a tracheostomy had saved their child’s life and this was the most important thing to them. Kihlstrom (1987) discusses structures in the brain that influence the way people reason and shape what counts as ‘common sense’, and advocates the use of reframing strategies at times of adversity. Reframing the circumstances of their child needing a tracheostomy allowed the parents in my study to see that there had been an instant positive change to their child’s breathing. This brought relief to parents for several reasons. Some parents were parents of a newborn baby and they expressed that at this stage they could finally relax and enjoy their new child for the first time. For other parents who had known for some time that one day their child would need a tracheostomy, it was the relief that their ongoing suffering had ceased. This study has highlighted that because a tracheostomy had a positive impact on their child’s breathing issues this allowed the initial pressures that parents were experiencing to decrease; to be buffered by grit and gratitude. Jonas (2005) discusses that revisiting and reconstructing one’s view of an experience imbues it with a different, usually more positive, meaning in the individual’s mind.

Parents' reframed their beliefs by thinking in a realistic and proactive manner because they now had a future to hold on to with their child, and this was a turning point for them to reconfigure their lives.

A key part of having a resilient mindset for the parents appeared to be their ability to be stretched to the limit but still be able to bounce back from adversity. Parents responded to the fact that due to the tracheostomy their child now had a future and they reconfigured or reframed their lives. Resilience is associated with the ability to 'bounce back or spring back' over time (Simpson, 2005). The characterisation of resilience as the ability to bounce back or recover from stress has been exhibited in the work of researchers who have explored resilience (Carver, 1998; Tugade & Fredrickson, 2004). It has also been discussed that bouncing back from stressful situations involves losing and then regaining homeostasis (Bonanno, 2004). I argue that having a child with a tracheostomy changed the parents' lives, making it impossible for them to go back to their former state. Parents often saw their experiences as a struggle which had been emotional and shocking but which served to strengthen their resolve and bolster them for the future. One of the central factors for the parents in my study that led to them bouncing back was the protective factors that they possessed and the resources that they accessed and utilised.

Conclusion to reframing (X domain)

A resilient mindset for the parents helped them come through adversity and allowed them to reframe. This realisation that I gained through my role as a researcher and listening to their stories has changed and shaped the way I felt about my care of families whose child needs a tracheostomy. Reframing played a significant part in how the parents' perceived and faced their situation. Parents showed the ability to deal with whatever came their way and exhibited a different view of their situation, allowing them to move forward with their lives. My findings from their early stories reveal that parents experienced a great deal of emotional upheaval, stress, uncertainty and shock, and yet found the ability over time to start reframing their beliefs once their child's life was out of danger.

CHAPTER 8: IN THE END

In this conclusion chapter, I first present an overview of my study, including my original contribution to knowledge. I then present the limitations of my study, followed by the implications to practice of my study and recommendations for future research. I close this chapter with a conclusion to the whole thesis.

At the start of my study it was clear from the literature review that little research had been undertaken that had qualitatively and/or longitudinally explored parents' experiences of having a child with a tracheostomy. I felt that research was needed to describe the journey these parents took, and using stories of parents' subjective experiences seemed an appropriate way to explore these journeys. As a nurse practitioner, I wanted to tell these stories and undertaking this research gave me this opportunity. I felt and still feel honoured to be able to do this. I wanted, as Frank (2010) suggests, to let the parents' stories 'breathe'. I felt this could happen by sharing their compelling perspectives on how having a child with a tracheostomy had affected their lives. By collecting and interpreting their stories, I have been able to theorise about how the adversities they experienced led them to become resilient in relation to their child's needs and to reframe their lives. This theorising has provided insights into parents' lives and experiences and created an avenue for incorporating this understanding into clinical practice.

After considering many concepts such as self-efficacy, motivation and cognitive adaption as contenders for the potential theoretical underpinning for my study, resilience was identified as the concept that could be best applied to the parents' experiences. Resilience was evident in the process that the parents went through to bounce back from the adversity of their child's life being at risk, and when they needed a tracheostomy to survive. Resilience was also evident in protective factors such as their own personal characteristics and support networks, which allowed the parents to reframe aspects of their lives in relation to their child's needs.

Original contribution of my study

Resilience has been an extremely popular and complex concept that many researchers have explored for over fifty years. However, this the first longitudinal qualitative study to use resilience as an underpinning theory to explain the journeys taken by parents whose child needed a tracheostomy. The ABC-X model developed by Hill (1949, 1958) and its further adaptations by McCubbin and Patterson into the Double ABC-X models (1982, 1983a, 1983b) has been a widely used model of resilience. I adapted the ‘ABC-X model’ (Ellingsen et al., 2014) by drawing on an integrated resilience perspective of the experiences of the parents. At the heart of my original contribution to knowledge is my ‘ABC-X Model of Parental Resilience and Reframing’, which pays direct attention to both the risk factors that the parents faced, and the protective factors they drew upon to respond to adversity and reframe their beliefs and lives.

The findings of this study and the model offer an original contribution to knowledge in terms of a more developed consideration of resilience, by considering the importance of seeing risk, adversity and resilience as things which are dynamic and develop over time. This longitudinal work adds to the existing resilience literature by moving away from the study of adversity as a time-limited concept. A second major contribution lies in the model, which provides a framework for engaging clinicians and other professionals to better appreciate the journeys taken by parents of children who need a tracheostomy. Understanding the risks that the parents perceive, how these risks accumulate and when these risks are likely to be at their most intense helps to clarify when and what types of support may be most helpful. Understanding the way in which risk, adversity, resources, and cognition mesh together to generate the process of reframing has the potential to improve the care of these families and focus service delivery. A final original contribution lies in the longitudinal narrative approach undertaken for the collection of data; this approach has allowed unique insights into the parents’ experiences to be revealed, with the potential for these stories to be shared with other parents.

Limitations

Whilst care was taken to develop a study that was robust and reliable inevitably the study has some limitations. As a novice researcher undertaking a study has inevitably resulted in much learning taking place and I have learned a great deal through the experience of undertaking the study.

Literature review

Selecting the approach for a literature review requires careful consideration as the two main approaches (systematic and narrative) have different purposes, strengths and limitations. Conventional systematic reviews address “narrowly focused questions (“puzzles or problems that require data”) for which a summary of the findings of studies that had asked that specific question might be helpful” (Thorne, 2018). My review did not intend to answer a narrowly focused question and the literature available to review was heterogeneous in terms of methodology, topic and methods. Systematic reviews tend to focus on studies using a more limited range of methodological approaches than I wished to include in my review. I chose to conduct a narrative review as I aimed to “deepen understanding with respect to a broad or complex issue” (Thorne, 2018). However, so as to ensure that my review encompassed the breadth of literature, I undertook a systematic approach to search for and appraise primary research. The heterogeneous nature of the data did not permit a single systematic approach to be applied to the critical appraisal process although the appraisal approaches used were robust and relevant. In systematic reviews focussing on clinical outcomes, the findings can be assessed for the certainty of evidence in order to make recommendations for clinical practice using Grading of Recommendations Assessment, Development and Evaluation (GRADE) (Guyatt et al., 2008). However, my appraisal aimed to consider the overall quality of the studies appraised in order to determine whether to include or exclude them from the review. I retained some papers where the quality was modest but which helped me to achieve the purpose of my narrative review which was to generate “clarification and insight” (Thorne, 2018). Narrative reviews are not purely descriptive as they aim to generate “clarification and insight” and the findings presented need to be subjected to critical reflection and the synthesis presented needs to be robust. I acknowledge that a limitation of my narrative review is that the synthesis could be stronger. Had this been the case it would have allowed me to develop a stronger theoretical basis for my study. However, as noted by Greenhalgh, Thorne & Malterud (2018), a narrative approach to reviewing literature should not be undervalued.

Recruitment and participants

This study is potentially limited by the relatively small sample of parents (n=12) recruited. However, this sample size is robust compared to the number of parents recruited to other qualitative studies of parents' experiences of having a child with a tracheostomy, which typically recruited eight parents, especially considering this study was longitudinal and offered parents the opportunity to engage at three time points. In defence of the relatively small sample size, the sample was diverse, as the age range of the children was wide and included those aged from birth to early teens; the children had a variety of diagnoses ranging from airway obstruction issues to neurological disorders. This diversity has allowed a picture to be built of the experiences of a range of parents and shows that despite different situations, many of their experiences were shared.

The findings are also limited by the fact that three parents withdrew from the study after the first interview (although their data were retained) thus reducing the number of planned interviews. However, although these parents withdrew the reasons for withdrawal were fully understandable, and all of the parents agreed for their data to be retained in the study. One mother found it difficult to continue talking about her experiences, so although she wanted her first interview to be part of this study, she did withdraw from further participation. Social issues for another mother and father impacted on their ability to stay in the study and they withdrew from further participation. Although fathers did make an important contribution to this study, more mothers (n=9) than fathers (n=3) were interviewed. This is not unusual in terms of research that considers parents' views on caregiving. For example in all the studies in the literature review relating to children with tracheostomies, mothers views are sought in more cases (n= 297) compared to fathers (n=74). In relation to this study, it could be that fathers found it difficult to talk about their experiences in-depth, and some of the fathers in this study had a smaller role in caring for their child's healthcare needs, which may in turn have limited their decision to participate.

Recruitment was limited to one specialist paediatric hospital, and although the catchment area is large, the parents' experiences of immediate and ongoing specialist care were limited to one paediatric hospital.

Despite these limitations to the sample my findings are based on 23 interviews undertaken with mothers and fathers over 14 months of fieldwork, so for a qualitative study involving a specialist group, this has resulted in a robust and valuable source of data.

Data collection

This study used unstructured interviews as its main method of collecting parents' stories, although I also made field notes and documented my ongoing reflections on data collection. One potential limitation arises because all of the parents that were involved in the study had a professional relationship with me as their nurse practitioner. I have reflected on this and I acknowledge that it took me some time to separate the two roles in the first two interviews. As part of my desire to really understand any influence my professional role had on my research, I undertook personal reflections and, as a novice researcher, I planned how to improve; I looked back to move forward. I did my best to ensure that my data collection (especially from the first two interviews) was not overly influenced by my development as a researcher; looking at the all of the interviews I did manage to access the thoughts and feelings of the parents and I did not note any points where my practitioner role interfered. When I read and re-read the transcripts from these interviews, I felt the content was powerful. I presented reflections of being a nurse practitioner/researcher at a student conference at University of Central Lancashire, and also reflected on this with my supervisory team.

There may also be some limitations in relation to my field notes. I recorded all my field notes by hand, however, sometimes especially in the time point one interviews, I did not immediately record my personal reflections in my reflective diary. This was often due to the impact of my clinical workload on return from interviews. I always arranged the interviews around the parents; often this meant meeting them in the early morning or afternoon, and hence I had to return to my clinical role once finished. This may have made my notes less detailed the longer I delayed the process. Greenhalgh (2013) discusses that creating an environment in which participants feel comfortable to share their stories is a challenge. Particular attention was given to the timing of the interviews around the parents' lives; sometimes this meant that parents who were being interviewed at home had to share their attention with me and their child, for example, interrupting the interview to suction their child's tracheostomy. However, I felt parents knew I understood that this was part of their everyday routine and we comfortably carried on after the procedure had been carried out.

Methodological approach

The field of narrative research is extremely diverse both methodologically and theoretically (Riessman, 2008). Narrative research is quite difficult to navigate and Ziebland (2013) advises that researchers need to consider the analytic tasks in identifying a story. A steep learning curve for me was the amount of data that was produced and how this needed to be analysed. Sutton and Austin (2015) point out that whatever data collection method the researcher is taking, the process will involve the generation of large amounts of data. Choices had to be made about how to analyse the data (which changed during the course of the study), and a particular challenge was what stories to include within the findings. Although my initial inexperience with analysing narrative data could have limited the findings, I was highly motivated to develop my skills and abilities to undertake the analysis. My intention was to do justice to the parents' stories and I undertook a comprehensive and deep analysis of data; the reader should have confidence in the findings of this study.

Scope of the study

The decision not to explore the stories of health and social care professionals within this study could be seen as a limitation as I cannot give an account of how these professionals believe their role impacted on the parents. It also meant that I was unable to bring professionals’ views on why care packages may break down. However, any study undertaken is limited in its scope, and I believe that focusing entirely on the parents’ stories has provided a robust basis for understanding their perspectives, and that subsequent research should address other perspectives.

Implications for practice

Four key implications for practice arose from this study:

1. The findings clearly show how emotionally distressed the parents were, especially in the early days, when they had to make big decisions and when the risk to their child’s life was at its peak. This is a crucial time for health care professionals to listen to and talk to parents, without overwhelming them with information. In those early days, parents need nurses who are tracheostomy trained to support them at the bedside, and specialist nursing care from someone who is easily contactable when additional support is needed. From my findings health care professionals working with these children and parents need to have a comprehensive understanding about tracheostomies.
2. Parents should be offered psychological support from psychologists, as it was clear from some interviews that certain parts of their journey were very emotional. These emotional feelings were often a surprise to parents and after interview they would often comment how talking about them with me had made them feel better. Ongoing support could also come from the family’s primary nurse, nurse practitioner or, where necessary, as part of support from psychological services within the Trust. Before undertaking this research study, psychological support for parents was not something that I had really appreciated would be of benefit to the parents. On reflection this type of support is an extremely important part of the parents’ journey and should be available to them. My intention will therefore be to liaise with psychologists (I have already presented my work at a conference with a psychologist) and to identify this as a gap in care for parents of a child with a tracheostomy.

3. The protective factors that parents drew upon in times of adversity empowered parents and helped them reframe. Based on the findings of this study, parents wanted to get home with their child as soon as possible, even if it was a daunting prospect. This is a significant time of challenges for the parents, and preparing them to take control at home and manage their child's care alone is paramount. This suggests that parents need more preparation than just how to change their child's tracheostomy tapes and the other core clinical skills that they are taught through competence based training packages. It seems important that health care professionals introduce opportunities for peer support, as parents in this study found this beneficial and would recommend it for future parents whose child needed a tracheostomy. [Note: as a result of conducting this study, I now routinely bring the online support group to the parents' attention as part of their discharge plan).
4. The 'ABC-X Model of Parental Resilience and Reframing' offers a framework for health and social care professionals to guide and support in helping care for families whose child needs a tracheostomy. Findings show that resilience was an important concept that allowed the parents to reframe. Utilising the concept of resilience around the care and support parents need could be useful to implement into practice. Professionals can potentially take actions to promote the resilience of parents of a child who needs a tracheostomy during times of stress and adversity. Resilience workshops should be offered to health and social care professionals which may help them to promote the concept**.**

Implications for future policy

Three key implications for policy are evident from my findings:

1. Discharge planning: An evidence based discharge planning policy for children with complex needs to be developed at either local or regional level. This should include existing guidance on discharge planning from non-

governmental organisations and should also be built on the views from clinical frontline staff and parents that have experience of complex discharges.

2. Co-ordination of care: A national policy for children with complex needs is needed with a comprehensive focus on co-ordination of care that focuses on the delivery and effective implementation of improved support and care packages at local level.
3. Patients with tracheostomies: A national policy set out by health care professionals with experience of adults and children with a tracheostomy. A resilience framework should be developed for professionals and patients in this field of health care that will help them to support their patients with tracheostomies and their carers. A focus of the policy would be for patients and their families to develop a resilient approach to managing life with a tracheostomy.

Recommendations for future research

Further research in this area of health care could expand on the findings in my study by exploring the following topics:

1. An important next step would be a case control study that measured parental resilience and how resilience is built over time and its relationship to having a child with a tracheostomy, with particular attention being paid to risk and protective factors to complement the qualitative findings of this study.
2. An appreciative inquiry study drawing on my ABC-X Model of Parental Resilience and Reframing: a study should be undertaken to explore further the risk and protective factors with a larger population of parents to examine how health professionals can best support them by reducing risk factors and promoting protective factors. This study could address how parents feel about the support they receive and interactions at these times, and how professionals feel about how they work in partnership with the parents when the risk to their child’s life is at its highest.
3. An ethnographic study is warranted on the perspectives of social and health care professionals on how they provide support to families for a child with a

tracheostomy**.** Social care professionals as well as health professionals have an enormous input on families with complex health care conditions and are often part of the team that help care for families whose child has a tracheostomy, but little is known about their particular needs or how they perceive they could promote resilience.

4. Utilising a realist design further research should focus on how parents achieve the outcome of competence in caring for their child with a tracheostomy. The focus would be on understanding the different context of care and operating mechanisms that lead to different outcomes.
5. Using an online survey for further exploration is warranted on parents' use of social media and the internet in two main areas**.** First, considering the experiences of parents using social media as a mechanism to establish a support network and exploring what motivates parents to become part of this group. This second area would be to explore why parents seek information on the internet, their responses to the information they find and how they use this information. This would be of particular interest in relation to those parents whose child is diagnosed with complex health care conditions.
6. A case study approach could explore the views of parents and professionals about how to foster a resilient mindset when there are delays in the child being given a diagnosis. This could generate findings that could promote well-being during a part of the journey that the parents in this study found particularly challenging.
7. A co–produced participatory research design to hear children's voices on their perspectives of having a tracheostomy. Although some children with a tracheostomy may be too young or have significant communication challenges which means that they could not engage in research, there is a cohort of children who could communicate through photo-voice, artwork, play and conversation. Findings from a child-centred study could substantially contribute to professional understanding about children's experiences.

Conclusion

A vast amount of research still needs to be undertaken so that we can understand and improve parents' experiences of their child having a tracheostomy. However, this study has added understanding of the experiences of parents of children who have a tracheostomy; in particular, its longitudinal nature has contributed considerably to the evidence base in this field. As Frank (2012, p3) notes, "human life depends on the stories we tell"; he goes on to say that stories "animate" and then they "instigate". This study has presented parents' stories in the hope that these will "animate" the reader to reflect on them and take these stories forward to instigate change with a sense of purpose. With the support of the professionals who already provide care, parents could be guided through adversity and the challenges they face so that they can more easily develop a resilient mindset, reframe and come out the other side. This study has helped me to understand better the experiences that parents go through when their child needs a tracheostomy. I hope that my findings will help to improve understanding of the journeys these parents have taken and improve practice, particularly in the early days when the families have to come to terms with their child needing a tracheostomy. As previously discussed this is an area of health care that is under-researched. At the moment the parents are 'going for it' and 'holding their own'; the findings of this study mean that professionals providing care and support to them should be able to help them 'go for it' and try to ensure that they are supported and do not feel alone whilst 'holding their own' and reframing these aspects of their lives.

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APPENDICES

Appendix 1 :Details of studies and critical appraisal of the literarure included in the review

Author, year, country	Research question or aim	Research design methods	Sample size	Results	Limitations
Children with Tracheostomies					
Cohen, et al (1998) USA.	Explore families perception of quality life of children who have undergone sleep aponea surgery versus tracheostomy	Quantitative –Parents completed a questionnaire	Parents (n=28)	It was determined that the quality of life was improved with sleep apnea surgery in comparison with tracheostomy.	Instrument not validated. Heterogeneity patient population
Harnick et al., (2003), USA.	Explore effects of a child having a tracheotomy tube on the degree of caregiver burden and overall health status of the care giver.	Quantitative- Pediatric tracheotomy health-status instrument.	Parents (n=154)	Parents caring for a child with a tracheotomy tube experience significant caregiver burden.	Sample unclear No detail as to why child had a tracheostomy. 0.001% incidence of missing data
Montagnino & Mauricio, (2004), USA.	Describe the impact of a child dependent on a tracheostomy/ gastrostomy primary caregiver with regards to stress and coping.	Quantitative. Impact on family scale crisis, oriented personal evaluation scales and demographic survey.	Parents (n=18) 50 families invited. 18 parents responded.	Findings suggested that caregivers were coping however data revealed disruption of social interaction within and outside the family.	36% response rate Only mothers completed the surveys.
Hopkins et al., (2008), UK	To assess the impact of paediatric tracheostomy on patients and their families (What was said).	Quantitative- Structured interviews & pediatric tracheotomy health status instrument.	Caregivers (n=26) 38 carers identified. 26 completed questionnaire.	Tracheostomy has wide ranging effects on the quality of life of both patient and caregiver affecting sleep, health emotional wellbeing relationships, and family life.	Small sample size for quantitative study. Not generalized to wider population. Carer as proxy for child's quality of life.

Author, year, country	Research question or aim	Research design methods	Sample size	Results	Limitations
McNamara et al., (2009) New Zealand.	Explore the experiences of parents in relation to the two humidification techniques being used in children with tracheostomies.	Qualitative Grounded theory. Semi-structured interviews RCT crossover study comparing Humidification aids.	Mothers (n=8) Nurses (n=4)	A core category was parents managing their child's care in response to a set of problematic and constraining states. Parents were seen to utilize strategies of constant checking and becoming the expert. This study reinforces the primary caregivers as managers of their child's care.	Small sample size mothers only. Pooled results of mothers and nurses for analysis. Data saturation not reached in all categories.
Berry et al., (2011), USA.	How does health information and sharing contribute to the quality of care received by children with a tracheotomy?	Qualitative-Interviews	Parents (n=8) Health care providers (n=15)	Improvements need to be made on patient tracheotomy records and personal health record platforms.	Children with a tracheostomy Neurological and airway related, however limited number of participants from each participant group.
Callan's et al., (2016), USA.	Purpose was to describe the family experience of caring for their child with a tracheostomy due to a compromised airway during the transition from hospital to home, and to identify types of support that families request to be successful caregivers.	Qualitative. Descriptive design. Focus groups.	Mothers (n=16) Fathers (n=2)	Family members confirmed that the transition to a 'normal' home with a child with a tracheostomy was challenging. They described the nature of these challenges in detail and identified specific enhancements in support that would help address these challenges.	No reason as to why the children had needed their tracheostomy. The principal investigator conducted the focus group interviews and was stated as being an expert in this field who would set aside prior knowledge and experiences of this patient group, however, this still may have caused bias.

Author, year, country	**Research question or aim**	**Research design methods**	**Sample size**	**Results**	**Limitations**
Children with complex respiratory needs					
Kirk & Glendenning (2002), UK.	What support parents wanted what they actually received and how congruent these were with professionals' perceptions.	Qualitative in-depth interviews.	Mothers (n=23) Fathers (n=10) Professionals (n=38)	Parents and nurses recognised the importance of easily accessible source of information and advice. The provision of practical help was also crucial.	Fathers under-represented.
Mentro & Steward (2002), USA.	To provide a more thorough understanding of the dynamic of care giving associated with medically fragile children	Qualitative Sense–Making Methodology. Interviews.	Mother (n=1)	There are positive and negative outcomes associated with care of medically fragile children.	Sampling not clear. Single case.
Tomment (2003), USA.	Qualitative Newman hermeneutic Interviews	What are the families health experiences of living with a child who is medically fragile What is the evolving pattern of family's health experience?	Parents (n=5)	Families changed from trying to gain control of their uncertainty to learning to live with uncertainty. Learning to live with uncertainty was a factor in school choice	Small sample size Sample not diverse
Brett (2004), UK	An exploration of parents of profoundly disabled children experience of support**.**	Qualitative. Phenomenology Interviews.	Parents (n=6) Profound disability /some respiratory issues.	Five themes 1. parents' feelings about support 2. Journey to accepting support 3. Support as a loss 4. Disability 5. Parent supportive relationship.	Sample characteristics missing. Small sample size.

Author, year, country	**Research question or aim**	**Research design methods**	**Sample size**	**Results**	**Limitations**
Rehm & Bradley, (2005), USA.	What are normal aspects of life for children and families who are medically fragile?	Qualitative Interviews.	Families (n=26)	Parents recognised positive aspects of their lives whilst acknowledging challenges. Concluding it was possible to have a good life that was not necessarily normal.	Sample characteristics of parents missing. Response rate missing.
Miller et al., (2009), Canada	To what extent can the constructs of relational, informational and management continuity; be discerned in the narratives of parent seeking and receiving services for their child with complex needs**.**	Qualitative. Semi structured interviews	Caregivers (n=46)	Relational informational and management continuity were all discernible in parents' narratives. Communication among providers was seen as integral to perceived continuity. Geographic institutional structures and practice providers attitudes were found to create barriers.	Fathers under-represented (n=2). Response rate missing.
Hobson & Noyes (2011), UK.	Describe roles of fathers engage in within the family with respect to the child with complex needs. Ascertain what fathers felt about their current roles.	Qualitative. In-depth interviews	Fathers (n=8)	Fathers enjoyed their caring role but at times found it stressful. They rejected the father-focused services as such provision would induce guilt. Positive relationships with their child and partners were reported.	Could have recruited more participants

Author, year, country	**Research question or aim**	**Research design methods**	**Sample size**	**Results**	**Limitations**
Woodgate et al., (2012), Canada.	To extend our limited understanding of how the changing geographies of care influence the ways that Canadian families with children with complex care needs participate in everyday life.	Ethnographic methods. Interviewing and photo voice.	Mothers (n=39) Fathers (n=29)	Parents described participation as a dynamic and reciprocal social process of involvement in being with others. Choices of safety acceptance accessibility and accommodation had to be present.	Not all parents were able to continue with either the second or the third interview.
Ward et al., (2015), New Zealand.	To report the findings on health professional's perceptions of beneficial care for seriously ill children and their families.	Qualitative. Critical realism. Focus groups.	12 health professionals. (Medical, nursing, allied health)	Five themes were identified: 1. Collaboration between health providers 2. Effective communication; 3. Expert skills. 4. Support for colleagues and, after-hours care availability. 5. Participants perceived the Trust model of care to be integral for children with serious illness, and their families in the community.	Bias during data interpretation and analysis due to first author being an insider researcher (no reflection of this given) Sampling not clear.

Author, year, country	Research question or aim	Research design methods	Sample size	Results	Limitations
Children on LTV					
Diehl et al., (1991), USA.	To identify the needs of parents of children with medically complex needs from their own perception and feelings.	Ethnographic. Focus group	Caregivers Female (n=71) Male (n=8)	A need for a care framework was identified training needs and services were discussed as being fragmented. A general lack of home care and how to plan was identified.	Majority of participants were female. Moderators guided list of questions was followed in the focus groups.
Wilson et al., (1998), Canada.	What is experience of mothers providing home care for the ventilator dependent child	Qualitative. Grounded theory. Interviews.	Mothers (n=16)	Mothers frequently needed help with immediate and often life threatening problems.	Children's health characteristics missing.
Noyes et al., (1999), UK.	To ascertain parents' experiences and views of the overall management and care their ventilator dependent child received.	Qualitative. Questionnaire Open ended questions	Families (n=7)	Multidisciplinary and multiagency service development is needed in order to meet the needs of ventilator-dependent children and their families.	Structured to gaining qualitative responses may have limited qualitative depth of data.
Kirk (2001), UK.	To assess how the transfer of responsibility of care from professionals to parents was negotiated.	Qualitative. Grounded theory. In-depth Interviews.	Mothers (n=23). Fathers (n=10). Professionals (n=44).	This study discovered that parents constructed transfer of responsibility for nursing care and the professionals supporting them in the home as being none negotiated.	A broad range of technology dependencies was included in the sample size.

Author, year, country	**Research question or aim**	**Research design methods**	**Sample size**	**Results**	**Limitations**
O'Brien (2001), USA.	An exploration of families' experiences with childhood technology dependency.	Descriptive naturalistic design. Unstructured interviews.	Mothers (n=11). Parents (n=4). .	Families identified frequent change and the unpredictable phenomena that was described as "living in a house of cards".	Generalizability of children's health conditions was limited and varied considerably with one child having a rare condition.
O'Brien et al., (2002), USA.	What are parents and home care nurses perceptions of rearing a technology dependent child?	Qualitative. Interviews.	Mothers (n=14) Fathers (n=2) Nurses (n=15).	Rearing the child who is technology dependent is similar to but different from raising other children. Parental communication and negotiation of child rearing expectations with home care nurses is essential.	Fathers sample size small. Response rate unclear.
Kirk et al., (2004) UK.	To explore the experiences of families caring at home for a technology-dependent child examine their practical needs and support in the community .	Qualitative. In depth interviews.	Parents (n=24). Health/social professionals (n=44).	Services in the community were not sufficiently developed to support this group of Families.	Response rate unclear. Theoretical sample and saturation unclear.
Kirk et al., (2005) UK.	To explore the experience of families caring at home for a technology dependent child, to examine their needs for practical and other support. Are services currently meeting their needs?	Qualitative. Grounded theory. In depth interviews.	Parents (n=24)	Parenting a technology dependent child alters the meaning of parenting. Professionals need to recognize that providing care has a substantial emotional dimension for parents.	Sampling not clear.

Author, year, country	**Research question or aim**	**Research design methods**	**Sample size**	**Results**	**Limitations**
Marlogan et al., (2004),UK	Describe the families' experience of the service they receive. Describe the care packages associated with long-term ventilation identify problems and best practice.	Mixed methods. Questionnaire with interview.	Mothers (n=13) Foster parent (n=1). Parent (n=1).	Following issues identified: 1. Discharge delay 2. Supplies 3. Social Isolation 4. Difficulties with respite care, 5. Finance 6. Education 7. Commissioning services.	Questionnaire not validated. Details of instrument missing. How many fathers in the study are missing?
Reeves et al., (2006), UK.	To understand the negotiation of care as experienced by parents of technology dependent child in hospital.	Qualitative. Semi structured interviews.	Parents (n=8).	Parents felt their roles as parents were not considered enough by nurses and that they tended to be seen as carers.	Sample characteristics of parents, children Health details, characteristics missing.
Mah et al.,2008	Describe the experinces of parents caring for a child with neuro muscular disease	Phenomenology	Parents (n=15)	Parents felt that they were their childs lifeline and their lives changed significantly once their child went on a ventilator	Fathers sample size small

Author, year, country	Research question or aim	Research design methods	Sample size	Results	Limitations
Mendes, (2013), USA.	Eliciting descriptions of ideal home nursing care for technology- dependent children from the perspective of their parents.	Qualitative. Descriptive design. Semi –structured interviews	Parents (n=7)	Data analysis revealed four components of ideal home nursing: 1. Competence in technical assessment 2. A caring manner 3. Relinquishing control of the child's care to the parents 4. Fitting in with family routines.	All the families were recruited from one pediatric home care agency.
Joseph et al., (2014), USA.	Surveys were used to measure stress coping quality of life.	Quantitative. Cross-sectional design. 1. Family inventory of life events 2. Family crisis orientated personal evaluation scale psychological general well-being.	Parents (n=71).	Parents who care for infants/ toddlers with a tracheostomy/ LTV at home were found to be in moderate distress. In addition, it was found that lower stress scores and better coping was related to better quality of life.	Recruitment was from online support group therefore sample selection was bias. Lengthy tools used (29 out of the 100 parents did not complete all of the survey). QoL scores given on one day.

Author, year, country	**Research question or aim**	**Research design methods**	**Sample size**	**Results**	**Limitations**
Giambra et al., (2014), USA.	A study undertaken to identify parental perceptions and experiences of communication with nurses who's chid was technology-dependent	Qualitative. Grounded theory. Semi-structured interviews.	Mother (n=9). Grandmother (n=1). Adoptive mother (n=1).	Theory of Shared Communication includes : 1. Questioning 2. Listening, 3. Explaining 4. Advocating 5. Verifying 6. Understanding and negotiating roles. To achieve the outcome of mutual understanding of care.	Small homogeneous sample, self-selection may have created bias. Gift cards were given to participants who completed the interview.
Mendes (2016), USA.	Hybrid Model of Concept development was used to integrate previous concept analyses and research on partnership between nurses /parents.	Qualitative Interviews.	Parents (n=7). Nurses (n=7).	Six characteristics of partnering were identified: 1. Respect, 2. Flexibility 3.Caring 4. Professionalism, 5. Communication, 6. Acknowledge parental control, and support for parents.	Nurses were recruited following recommendation by parents in the study.
Giambra et al., (2017), USA.	The aim was to expand the understanding of communication between parents of hospitalized Technology-Dependent child and their nurses originally detailed in the theory of shared communication (TSC)**.**	Grounded theory, Semi-structured interviews.	Father (n=2). Mother (n=3). Nurses (n=9).	Parents verified the concepts of the TSC and relationships among them. Nurses' perceptions of communication with parents reflected the same parents identified that included respect for own and other's expertise.	Self-selection created may have bias. Parents' delays in making journal

Table A: Critical appraisal of qualitative literature. **Key**: Y= Yes; N= No; CT= Can't tell

Screening questions → Studies ↓	**Was there a clear statement of the aims of the research?**	**Is a qualitative methodology appropriate?**	**Was the research design appropriate to address the aims of the research?**	**Was the recruitment strategy appropriate**	**Was the data collected in a way that addressed the research issue**	**Has the relationship between researcher and participants been considered?**	**Have ethical issues been taken into consideration?**	**Was the data analysis sufficiently rigorous?**	**Is there a clear statement of findings?**	**How valuable is this research**	**Conclusion on critical appraisal**
Berry et al., 2009	Y	Y	Y	Y	Y	CT	N	Y	Y	Strategies were discussed to improve home-based records for tracheostomy care.	Despite lack of clarity about relationship between researcher and participants and standards of ethics this study has merit to be included
Brett, 2004	Y	Y	Y	Y	Y	N	Y	CT	Y	Deepened the understanding of the support that parents require at vulnerable times.	A well-reported study with content highly relevant to the review.
Callans, et al., 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Highlights challenging issues about transition to home with a child who has tracheostomy	A relevant study because of its focus on transition of a child with a tracheostomy

Screening questions → **Studies** ↓	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion On critical appraisal
Diehl et al., (1991)	Y	Y	CT	CT	Y	N	N	Y	Y	This study identified an important need for a care framework for children on LTV	Despite weaknesses across four areas of reporting this study was included in the review because it identified important findings for children on LTV
Giambra et al., 2014	Y	Y	Y	Y	Y	N	CT	Y	Y	Reports on theory of Shared communication as important to apply to practice.	Despite lack of transparency about researcher /participant relationship and informed consent overall a relevant study
Giambra et al., 2017	Y	Y	Y	Y	Y	N	CT	Y	Y	The integration of nurse and parent perspectives, and shared communication can enhance communication	Even though it was unclear how ethics was obtained an important study to include in the review

Screening questions → **Studies** ↓	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion On critical appraisal
Hobson & Noyes, 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	An unique insight into how fathers enjoyed the caring role for their child with complex needs but at times found it stressful	A well-reported study and its content relevant to the review
Kirk, 2001	Y	Y	Y	Y	Y	N	Y	Y	Y	Home provided parents with a sense of control when negotiating care highlights the importance of power changes not leading to conflict.	Although unclear about participant researcher relationship the study had important findings to include in the review
Kirk & Glendinning , 2002	Y	Y	Y	Y	Y	N	Y	Y	Y	Both parents and nurses recognised the importance of easily accessible information and advice.	Despite lack of clarity about critical examination of the researcher role a worthy study to include in the review

Screening questions → **Studies ↓**	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion on critical appraisal
Kirk et al.,2004	Y	Y	Y	Y	Y	Y	Y	Y	Y	Highlights the importance that services in the community need to be sufficiently developed to support families on LTV.	A relevant and well-presented study for this review.
Kirk et al.,2005	Y	Y	Y	Y	Y	Y	Y	Y	Y	Professionals must recognise that providing care to their child is emotional for parents	A justifiable and well-presented study to include in the review
Mentro & Steward, 2002	Y	Y	Y	CT	Y	N	N	Y	Y	A single case with positive and negative outcomes of caring for a medically fragile child	Despite a weakness across three areas of reporting warrants merit to be in the review because of the variable outcomes reported

Screening questions → **Studies** ↓	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion on critical appraisal
McNamara et al., 2009	Y	Y	Y	Y	Y	N	Y	Y	Y	Some important findings about care giving/use of humidification for practice	Content relevant to the review despite lack of reporting on researcher participant relationship
Miller at al., 2009	Y	Y	Y	Y	Y	N	N	Y	Y	Highlights relational informational and management continuity were all discernible in parents' narratives	Lack of clarity on ethical issues such as informed consent however warrants inclusion in the review
Mendes et al., 2013	Y	Y	CT	Y	Y	N	Y	Y	Y	Adds to the evidence by developing four components of ideal home nursing	Although hard to ascertain if the research design was appropriate it was a relevant study to include in the review

Screening questions → **Studies** ↓	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion on critical appraisal
Mendes, 2016	Y	Y	Y	CT	Y	N	N	Y	Y	Highlights six characteristics of partnering care for parents and nurses	Although there was a lack of reporting in three areas this study has merit to be included in the review
Noyes et al.,1999	Y	Y	CT	Y	Y	Y	CT	Y	Y	Important implications for practice which show that service provision for children on LTV should be developed further in order to meet the needs of these families	Although responses may have been limited to gaining qualitative depth of data an important study to include in the review
O'Brien, 2001	Y	Y	Y	Y	Y	N	Y	Y	Y	Increases the understanding of providing optimal care to families whose child is on LTV	A worthy study to include in the review
O'Brien et al., 2002	Y	Y	Y	Y	Y	N	Y	CT	Y	Important findings about parental communication and negotiation of child rearing	Although response rate unclear merits inclusion in the review

Screening questions → **Studies** ↓	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion on critical appraisal
Rehm & Bradley, 2005	Y	Y	Y	CT	Y	N	N	Y	Y	Adds to the evidence that parents recognise positive aspects of their lives whilst acknowledging challenges	Warrants inclusion despite lack of reporting in three areas where insufficient detail was given.
Reeves et al., 2006	Y	Y	Y	CT	Y	CT	Y	Y	Y	Important findings show that negotiation of care between parents and nurses is problematic	A lack of concise reporting on recruitment and researcher relationships with parents warrants inclusion in the review
Tomment, 2003	Y	Y	Y	Y	Y	N	Y	CT	Y	Gave some insight into how families gain control of their lives with a child who is medically fragile even though there is uncertainty in their lives.	Although a lack of clear and concise method for data analysis this study has sufficient merit to be included in the review.

Screening questions → **Studies** ↓	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research	Conclusion on critical appraisal
Wilson et al.,1998	Y	Y	Y	Y	Y	N	CT	Y	Y	Develops an important Model of Absolute Involvement consisting of the attributes of mothering, meeting the demands of caregiving, and employing strategies of care	Although some ethical issues missing the study had sufficient merit to be included in the review
Woodgate et al., 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Important findings show parents describe participation as a dynamic and reciprocal social process of involvement in being with others	A well-presented study with important context for the review
Ward et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	This study extends the current understanding of models of care for children with complex health care needs	A well reported and relevant study to be included in the review

Table B: Critical appraisal of the quantitative literature.

Screening questions → Studies ↓	**Does the study address a clearly focused issue?**	**Did the authors use an appropriate method to answer their question?**	**Was the cohort recruited in an accept-able way?**	**Was the exposure accurately measured to minimize bias?**	**Was the outcome accurately measured to minimize bias?**	**Have the authors identified all important confounding factors?**	**Was the follow up of subjects complete and long enough**	**What are the results of the study?**	**How precise are the results?**	**Do you believe the results?**	**Can the results be applied to the local populati-on?**	**Do the results of this study fit with other available evidence?**	**Conclusion on critical appraisal**
Cohen et al., 1998	Y	Y	Y	N	CT	CT	N	The quality of life was improved for children who had sleep apnoea surgery compared to children with a tracheostomy	76 question-naires sent out 46 returned	Y	Y	CT	Despite four areas of weakness of reporting in this study it was included in the review because of its relevance and outcome for a child with a tracheostomy
Harnick et al., 2003	Y	Y	Y	Y	Y	CT	N	Parents caring for a child with a tracheostomy experience caregiver burden	All 154 question-naires returned	Y	Y	Y	Only one timepoint was included and no rationale for this however warrants merit to be included in the review

Screening questions → **Studies** ↓	Does the study address a clearly focused issue?	Did the authors use an appropriate method to answer their question?	Was the cohort recruited in an acceptable way?	Was the exposure accurately measured to minimize bias	Was the outcome accurately measured to minimize bias?	Have the authors identified all important confounding factors?	Was the follow up of subjects complete and long enough	What are the results of the study?	How precise are the results?	Do you believe the results?	Can the results be applied to the local population?	Do the results of this study fit with other available evidence?	Conclusion on critical appraisal
Hopkins et al., 2008	Y	Y	Y	Y	Y	Y	N	Tracheostomy has wide ranging effects on the quality of life of both patient and caregiver	38 carers 26 completed questionnaires	Y	Y	Y	A relevant study with content that was important to include in the review however only one timepoint included
Joseph et al., 2014	Y	Y	CT	Y	Y	CT	N	Parents who care for infants with a tracheostomy /LTV at home were found to be in moderate distress	29 out of 100 parents did not complete the survey	Y	Y	Y	Despite three areas that lacked rigorous reporting a relevant study to be included in the review
Montagnino & Mauricio, 2004	Y	Y	Y	Y	Y	Y	N	Caregivers were coping however data revealed disruption within and outside the family of social interaction	Out of 50 questionnaires sent 18 responses	Y	Y	Y	Content highly relevant to this review despite one timepoint

Screening questions → **Studies** ↓	Does the study address a clearly focused issue?	Did the authors use an appropriate method to answer their question?	Was the cohort recruited in an accept-able way?	Was the exposure accurately measured to minimize bias	Was the outcome accurately measured to minimize bias?	Have the authors identified all important confounding factors?	Was the follow up of subjects complete and long enough	What are the results of the study?	How precise are the results?	Do you believe the results?	Can the results be applied to the local population?	Do the results of this study fit with other available evidence?	Conclusion on critical appraisal
Smith et al., 2003	Y	CT	Y	Y	CT	CT	N	Children with a tracheostomy can achieve successful education in mainstream and special schools	Most of the question-aires incomp-lete	N	CT	CT	Poor reporting methods and no analytical process stated made this study unsuitable for inclusion

Table C: Critical Appraisal of mixed method literature using Good Reporting of Mixed Methods Study (GRAMMS; O'Cathain et al., 2008).

Screening questions → **Studies** ↓	**1. Describe the justification for using a mixed methods approach to the research question?**	**2. Describe the design in terms of the purpose, priority and sequence of methods?**	**3. Describe each method in terms of sampling, data collection, and analysis?**	**4. Describe where integration has occurred, how it has occurred and who has participated in it?**	**5. Describe any limitation of one method associated with the presence of the other method?**	**6. Describe any insights gained from mixing or integrating methods?**	**Conclusion on appraisal**
Margolan et al., 2004	Methods used were a questionnaire that incorporated questions from a quantitative and qualitative data perspective, these methods together, gave a greater diversity of divergent views.	The sequence of methods used was a questionnaire that was developed following a literature search to identify issues relevant to this group of children (LTV) which seemed a reasonable way to provide the foundations of what to ask parents.	Method X: Sampling well presented Method Y: Data collection (questionnaire): well presented with a range of clinical conditions, ages duration and types of ventilation included to what respiratory support the child received to more probing questions about support received and different aspect of training needs Method Z: Data analysis not clearly described.	Integration of the data took place in a structured format and most of the quantitative data was presented separately in a table. The qualitative data was discussed under headings that were from the questionnaire questions.	There was poor reporting of the qualitative side of the study with no direct quotes used from parents. Parents' views could have been captured and the richness of this was missing to complement the quantitative data.	The mixing of methods did not add any great depth to the empirical findings, in particular the quantitative data was not used to its full potential no statistical analysis was undertaken.	Despite some aspects of the study that could have been reported more strongly overall has sufficient merit to be included in the review.

Appendix 2: CASP qualitative appraisal tool (2018)

1. Was there a clear statement of the aims of the research?	Yes No Can’t tell	HINT: Consider • what was the goal of the research • why it was thought important • its relevance
2. Is a qualitative methodology appropriate?	Yes No Can’t tell	HINT: Consider • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the tight methodology for addressing the research goal
3. Was the research design appropriate to address the aims of the research?	Yes No Can’t tell	HINT: Consider • if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)
4. Was the recruitment strategy appropriate to the aims of the research?	Yes No Can’t tell	HINT: Consider • If the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part.

5. Was the data collected in a way that addressed the research issue?	Yes No Can’t tell	HINT: Consider • If the setting for the data collection was justified • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) • If methods were modified during the study. If so, has the researcher explained how and why • If the form of data is clear (e.g. tape recordings, video material, notes etc.) • If the researcher has discussed saturation of data.
6. Has the relationship between researcher and participants been adequately considered?	Yes No Can’t tell	HINT: Consider • If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7.Have ethical issues been taken into consideration?	Yes No Can't tell	HINT: Consider • If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee
8.Was the data analysis sufficiently rigorous?	Yes No Can't tell	HINT: Consider • If there is an in-depth description of the analysis process • If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process • If sufficient data are presented to support the findings • To what extent contradictory daa are taken into account. • Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?	Yes No Can’t tell	HINT: Consider whether • If the findings are explicit • If there is adequate discussion of the evidence both for and against the researcher’s arguments • If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) • If the findings are discussed in relation to the original research question
10. How valuable is the research?	Yes No Can’t tell	HINT: Consider • If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Critical appraisal skills programme (2010)

CRITICAL APPRAISAL SKILLS PROGRAMME (CASP): Making Sense of Evidence
12 Questions to Help You Make Sense of a Cohort Study

General Comments

• Three broad issues need to be considered when appraising a cohort study.

- Are the results of the study valid?
- What are the results?
- Will the results help locally?

• The 12 questions on the following pages are designed to help you think about these issues systematically.

• The first two questions are screening questions and can be answered quickly. If the answer to those two is "yes", it is worth proceeding with the remaining questions.

• There is a fair degree of overlap between several of the questions.

• You are asked to record a "yes", "no" or "can't tell" to most of the questions.

• A number of hints are given after each question. These are designed to remind you why the question is important. There may not be time in the small groups to answer them all in detail!

A. Are the results of the study valid?

Screening Questions

1. Did the study address a clearly focused issue?

Yes Can’t Tell No

HINT: A question can be focused in terms of:

- the population studied
- the risk factors studied
- the outcomes considered
- is it clear whether the study tried to detect a beneficial or harmful effect?

2. Did the authors use an appropriate method to answer their question?

Yes Can’t Tell No

HINT: Consider

- Is a cohort study a good way of answering the
- question under the circumstances?
- Did it address the study question?

Is it worth continuing?

Detailed Questions

3. Was the cohort recruited in an acceptable way?

Yes Can’t Tell No

HINT: We are looking for selection bias which might compromise the generalisability of the findings:

- Was the cohort representative of a defined population?
- Was there something special about the cohort?

- Was everybody included who should have been included?
-

4. Was the exposure accurately measured to
minimize bias?
Yes Can’t Tell No
HINT: We are looking for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measures truly reflect what you want them to (have they been validated)?
- Were all the subjects classified into exposure groups using the same procedure?
-

5. Was the outcome accurately measured to minimize bias?
Yes Can’t Tell No
HINT: We are looking for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measures truly reflect what you want them to (have they been validated)?
- Has a reliable system been established for detecting all the cases (for measuring disease occurrence)?
- Were the measurement methods similar in the different groups?
- Were the subjects and/or the outcome assessor blinded to exposure (does this matter)?
-

6. A. Have the authors identified all important confounding factors?
Yes Can’t Tell No
List the ones you think might be important, that the authors missed.

6. B. Have they taken account of the confounding factors in the design and/or analysis?
Yes Can’t Tell No
HINT:
Look for restriction in design, and techniques eg modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

7. A. Was the follow up of subjects complete enough?
Yes Can’t Tell No

7. B. Was the follow up of subjects long enough?
Yes Can’t Tell No
HINT:

- The good or bad effects should have had long
- enough to reveal themselves
- The persons that are lost to follow-up may have
- different outcomes than those available for
- assessment

- In an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?

B. What are the results?
8. What are the results of this study?
HINT:

- What are the bottom line results?
- Have they reported the rate or the proportion between the exposed/unexposed, the ratio/the rate difference?
- How strong is the association between exposure and outcome (RR)?
- What is the absolute risk reduction (ARR)?
-

9. How precise are the results? How precise is the estimate of the risk?
HINT: Size of the confidence intervals

10. Do you believe the results?
Yes Can’t Tell No
HINT:

- Big effect is hard to ignore!
- Can it be due to bias, chance or confounding?
- Are the design and methods of this study sufficiently flawed to make the results unreliable?
- Consider Bradford Hills criteria (eg time sequence,dose-response gradient, biological plausibility, consistency).

Is it worth continuing?

C. Will the results help me locally?
11. Can the results be applied to the local population?
Yes Can’t Tell No
HINT: Consider whether

- The subjects covered in the study could be sufficiently different from your population to cause concern.
- Your local setting is likely to differ much from that of the study
- Can you quantify the local benefits and harms?
-

12. Do the results of this study fit with other available
evidence?
Yes Can’t Tell No
One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making. However, for certain questions observational studies provide the only evidence. Recommendations from observational studies are always stronger when supported by other evidence.

Appendix 3: Appraisal for mixed methods studies (O'Cathian, Murphy, & Nicholl, 2008)

As a result of the research and analysis the study produced the Good Reporting of a Mixed Methods Study (GRAMMS) framework to encourage quality reporting of mixed methods studies. This six-item framework includes prompts about the 'success of the study, the mixed methods design, the individual qualitative and quantitative components, the integration between methods and the inferences drawn from completed studies' (O'Cathain et al., 2008:92). The GRAMMS includes the following set of quality guidelines:

1. Describe the justification for using a mixed methods approach to the research question
2. Describe the design in terms of the purpose, priority and sequence of methods
3. Describe each method in terms of sampling, data collection and analysis
4. Describe where integration has occurred, how it has occurred and who has participated in it
5. Describe any limitation of one method associated with the presence of the other method
6. Describe any insights gained from mixing or integrating methods

Appendix 4: Participant Information sheet

Participant Information Sheet

A narrative inquiry into stories parents tell of having a child with a tracheostomy.

I would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it involves for you. I will go through this information sheet with you and answer any questions you might have. Please take time to read the following information carefully, if there is anything that is not clear, or if you would like more information, do not hesitate to ask.

What is the purpose of this study?

The purpose of this study is to gain an understanding of your experiences and views of the first 12 months after your child had their tracheostomy inserted. I am interested in the views and experiences of both parents.

Why have I been invited?

You have been selected as you are a parent of a child who has recently had a tracheostomy. The study will involve parents of another eight to twelve children who have had a tracheostomy.

What does the study involve?

The study involves three interviews carried out over 12 months. The first interview would take place in the hospital before your child is discharged from Alder Hey. The second and third interview would take place after you have gone home at 3 and 12 months after your child had their tracheostomy formed. I will arrange these interviews at a time and place most suitable for you, such as your home. If we cannot arrange a suitable time or place for an interview, I will ask you if you would like to be interviewed on the telephone. I am interested in interviewing both parents, where this is appropriate. Ideally I would like to interview you separately from your partner, but if you prefer to be interviewed together then that is fine. With your permission I would like to record the interviews to help me remember the important issues you have told me.

Do I have to take part?

No, it is up to you whether you would like to take part in the study, not taking part will not affect the standard of care you or your child receives. If you decide to take part and then later change your mind at any time no one will mind.

What will happen to me if I take part?

If you agree to take part I will organise to interview you before you are discharged from hospital. This will take place after you have signed a consent form. A phone call will be made to you around two and eleven months after being at home to organise the second interview and then a third interview. Each of these interviews may last for about one to two hours but I will check with you at the start of the interview how much time you have available. Notes will be made by me during these interviews unless you do not agree to this. All audio recordings will be destroyed once they have been typed out and checked for accuracy.

What will happen to the information?

Any information collected will be treated confidentially, unless information is shared during the interview about someone being harmed in which case this may have to be shared with others. You or your child would not be identified in any information reported from the study. If you decide to take part the interviews will be audio recorded, typed out, and stored securely. If you change your mind about taking part after interview you will have up to 4 weeks to withdraw consent if you so wish. If you change your mind after taking part in one interview you do not have to continue to take part in the other interviews.

What are the benefits of taking part?

I hope that the information gathered may benefit future families of children who have a tracheostomy. There will be no direct benefit for you in taking part in the research.

What are the possible disadvantages of taking part?

There should not be any disadvantages from taking part except for the time it takes for you to partake in the interviews. Discussing your experiences of your child having a tracheostomy may cause you to be upset. If you do become upset you can decide whether you want to continue or not. I can help you seek further support if you feel you require this. This support could be from a parent group, health professionals you are already in contact with or other support services. If you do feel that you need more support we can discuss what would be appropriate for you.

Further information

If you have any concerns about the research and wish to speak to someone independent please contact: Patient Advisory Service at Alder Hey Children's NHS Foundation Trust on 0151 252 5374 or Dot Lambert (Research Manager) on 0151 252 5673.

If you would like any further information about this study please contact either myself:

Alison Flynn
ENT Nurse Specialist

Alison.flynn@alderhey.nhs.uk
0151 228 4811 ex 3757
Work mobile 07964118868.

Or supervisory team at
bcarter@uclan.ac.uk
brayl@edgehill.ac.uk
adam.donne@alderhey.nhs.uk

Thank you very much for your time in reading this information leaflet and for considering taking part in the study.

Appendix 5: De-brief sheet

Debriefing sheet for parents

A narrative inquiry into stories parents tell of having a child with a tracheostomy.

Thank you for taking part in this study. Your experiences and views are very important to us. The information you have shared with me will be now typed out and confidentiality maintained.

If you have felt distress because of the interview please discuss this with me and we can decided together if you need any further support.

Some useful contacts

You're Health Visitor

Children community nursing team

Aid for children with tracheostomies; a parent led association www.actfortrachykids.com

Face to face support is a service in the Alder Hey which offers emotional support to any parent/carer of a child with disability or complex needs.

www.scope.org.uk/face2face .

Thank you for your time and support to this project

Alison Flynn Alison.flynn@alderhey.nhs.uk

Appendix 6: Data transcripts

Interview One – Tom Greene family (pseudonym)

With Mum and Dad together

On 29/7/13

Tom had a tracheostomy tell me a story about this (me)

Erm laugh…. what kind of thing would you like to know (mum)

Tell me a story from the beginning (me)

It was terrifying really wasn't it he was taken away from us straight away and he just wasn't breathing on his own so it's was bit (mum)

And it was the worst thing as you were not made aware that he had any issues whilst he was in the womb erm the moment he was born they had a respiratory table there in the room so he was on their for 45 minutes surround by about 6 or 7 doctors erm didn't hear him cry or make any noise at all just new there was a problem it wasn't for about 20 min until someone come over and said he got breathing difficulties erm we doing everything we can (Dad)

We speak to you as soon as possible, so that was it and we sat there watching them do all this to our brand new baby and really not knowing what's going on (Mum)

All a bit of a blare wasn't it (dad)

Yes definitely (Mum)

They didn't take him down to ICU (dad)

Special care unit (Mum)

Special care unit we were still none the wiser the doctors knew he was having breathing difficulties couldn't understand why they were checking

his airways checking his heart doing all they can we knew they were doing all they can silence …. (Dad)

And then when we when we were sorted out and everything and we gone down to the special care ward we were told we be transferred to DGH 2**,** so immediately you then start worrying even more (Mum)
Silence…….

They were very good in DGH 2 as well weren't they they checked him over when we arrived and just basically said to us he going to need to be reviewed by a specialist ENT with small enough equipment to see what the problem is so they arranged it quite quickly didn't they to be transferred to hear, so he could be checked over and then we meet the fabulous ENT consultant 1, (laugh laugh mum)

While we were in DGH 2 it had been he was 2/3 days old before we were transferred here and wasn't till the second day that (mum) actually got to hold him it was about 60 / 70 hours as say when you got a new born to actually get your first hold (Dad)

Think that was actually the hardest bit not being able to hold him (mum)

With 7 or 8 wires coming off him yeah and then we were transferred straight here so them first 3 days was all (dad)

Travelling really (mum)
Silence …….

You just didn't have time to think you in there and 45 minutes later he is taken away three hours later mum been told been transferred to DGH 1 and then when tried to reach DGH 1 he saying he got this here he is and we

doing all we can however again no one can give you an answer as to what's wrong and then you being told you are being transferred to paediatric hospital 1 so again it's on the move again and you got no time to think or take it all in at that point (Dad)

Or even express milk ha there was no time for any of that was there (mum)
Silence ………

So what happened when you got to paediatric hospital 1? (me)

It was quite late on wasn't it when we arrived so it was sort of we booked into a hotel erm (Mum)

It was about 9 o clock wasn't it (Dad)

It was about 9 o'clock yeah (Mum)

We came straight over (Dad)

We came straight over to the hospital to see him they basically reassured us he was ok (Mum)

Stable (Dad)

Yeah and he was going to be well looked after obliviously he was on ICU so not much more sort of one on one care you can get really so Its them 3 letters the ICU it's like me mam had passed away couple of months before going from HDU to ICU and all the alarms (Mum)

First time I had ever heard of ICU was when mums mam was taken there so you start to imagine what's going why did you need such care must be something really bad with him again the first couple of days a blare of information and being passed from one specialist to another you got family

ringing you up asking what is going on and y can’t give them a straight answer (Dad)

Yeah (mum)

And you got Sarah to worry about so it’s like are daughter so you don’t really know (Dad)
Anything (mum) laugh ……Silence ………………………………..

So what happened after the first few days? (me)

He had is endoscopy is that what it is ENT consultant 1 basically told use everything that he had found with regards to his jaw being small his cleft palate nostril being very thin,(Mum)

Uvula (Dad)

Uvula being split (Mum laugh)

They thought he was Pierre Robin at first just hit us with all this information (Dad)

Yeah (Mum)

This is my findings this is what we are going to look at this is what could happen in the future.is like wow hang on, from a couple of days of bleared then actually sitting down with someone one on one he done an investigation and then you are told this this this he going need this in a couple of years he need this this in a few months he need this operation it’s like (Dad)

It’s devastating isn’t it (Mum)
Silence …………………

Did they mention a tracheostomy? (me)

Tracheostomy and his heart problem (Dad)

Yeah (mum)

Erm they told us about possible Di George syndrome didn't he but when he said Pierre Robin or Di George no he didn't tell us about Di George (Dad)

No no he didn't have his test (Mum)

No no he didn't have his genetic test (parents together)

They said do genetic test possible tracheostomy to keep him stable erm he got this cleft palate which might grow out or might have do an operation on his cleft palate small jaw and this large tongue which was suffocating him so hopefully he grow out of it errm (Dad)

Facial reconstruction because his nostril his left side being so thin (Mum)

Might need an operation on his nose (Dad)

Yeah (Mum)

And his uvula might need an operation that it's like half a dozen operations to your baby this is the first person who has sat down after a whirlwind couple of days then (Dad).

Mmm they done bloods and everything and his calcium levels were really low as well which they were obviously concerned about so they did the genetic testing and they came back and told us he had di George so again it's something new and you don't know anything about it they couldn't really tell us there and then what to expect (deep breathe) so we did the stupid well I did anyway went stupidly look on Google and terrified myself but when we actually spoken to the genetics team it wasn't that bad it wasn't half as bad as we thought it was going to be (Mum)

No said structurally he is who he is so not going be as bad (Dad)

Yeah not going to change (Mum)

One part of it is the learning difficulties but it not the high end of learning difficulties it's only some people you don't even notice it (Dad).

Very mild (Mum)

Yeah very mild form of leaning difficulties then you read things about facial disfigurements long fingers and this that the other it's like (Dad)

Schizophrenia (Mum)

Ye mental health issues and (Dad)

But again when we spoke to them it was fine it all seemed to be totally blown out of proportion really didn't it (Mum)

Don't trust the internet (Dad)

But then in I think after we spoke about the tracheostomy when we did look that up I felt better about it because it didn't seem as bad as I thought it was so things (Mum)

For me personally when you told us all that information for his tracheostomy as a parent the last thing you want is a visual disability for your child for some reason that's worse than having a mental issue (Dad)

Mmm people might see it and judge you people pity you because your child got this in (Mum)

Visual (Dad)

Yeah something they can see (Mum)
Silence …..
So that was your first feelings was it about the tracheostomy? (me)

Yeah then when you watching him in his incubator and he de sats all the time every half hour to an hour he going blue and black and they bagging him that side of it and you think that's not fair on him if this simple task for us stops him going through that surely that's a better thing (Dad)

Silence ………

So how long had you been at paediatric hospital 1 before he had his tracheostomy? (me)

June 16 he had his trachy about (Dad)

3 weeks ish (Mum)

Just under 3 weeks (Dad)

ENT consultant 1 was very sort off he was trying to hold off as long as he could to do it wasn't he as he wasn't 100 % sure that that was the right way to go and he keeps saying now doesn't he feels a bit sorry that he had to do it but he been so much more stable since he had it done that we got no concerns what so ever over his decision at all very happy he done it really (Mum)
At the start you always thought that something else you knew weren't just his upper airways (Dad)

Airways (Mum)

You always had a feeling that something else was causing his de sats so tired NG tube (Dad)

No NPA tube (Mum)

NPA tube up his nose so we will try that way as that not scary as having a tracheostomy the tracheostomy a last resort tried to put that in because of his nostrils erm his right nostril actually flared up because of all the trauma of the inspection and incubation (Dad)

Ventilation (Mum)

Yeah ventilation tubes and things so that was quiet swollen so he struggled to get it up there at first but when they did get it up it weren't helping still with the de sats he was still de stating so he really didn't want to go ahead with the tracheostomy until other teams come back and ruled other things out but you kept seeing these de sats and as only thing there for him as parents (Dad)

All you want is for your baby to be ok (Mum)

Stable (Dad)

Silence ……..

He was booked in wasn't he for his tracheostomy so we spent all day all morning with him while he was hungry because he was starved as going under general anaesthetic and everything and then he went down to theatre so we went off and did other things and they phoned us to say he was back no they phoned us to say ENT Consultant 1 wanted to speak to us didn't they so instantly we were worried even though they said nothing to worry about so we got back to ICU and tom was there without a tracheostomy so we were a little (Mum)

And no ENT Consultant 1 (Dad)

Yeah no ENT Consultant 1(Mum)

So when he did turn up anyway he explain to us he tired the NPA again and it went in much better and everything looked stronger and he just didn’t think going ahead with the tracheostomy was the right thing to do (Mum)

At that time (Dad)

At that time (Mum)

Was only fair to give him a chance with NPA tube (Dad)

So they put a longer one in didn’t they (Mum)

Yeah (Dad)

So it totally by passed his whole upper airway and he said if de stats carry on with this bigger tube in then they will have to go ahead with a tracheostomy because (Mum)

They know it’s an upper airway (Dad)

They know it’s that that problem so it was another week wasn’t it while he was on this and he was so unhappy wasn’t he he was just you could see it in his eyes just looking him how unhappy and uncomfortable he was and he was lot more stable wasn’t he so it was decided then that the week after he would have his tracheostomy done (Mum)

That first one I actually went over there at lunch time the day before ENT consultant 1 was there saying could I have a quick word with you mum was over here with Sarah I think or doing lunch or something so I went in I just want go through this consent form for the tracheostomy tomorrow so he took me off to a private room he was going through errm the actual procedure what the consequences could be as well and on there is a list of death and the thing is part of what could happen (Dad)

Airway compromise (Mum)

Yeah airway compromise and all these things and he kind of saying the NPA tube wasn't as stable or secure wasn't as good as a tracheostomy would be in the long term and he saying the thing is you could cut this vein and that could cause you problem or risk of compromise or you could die , so as parents you told this might be more secure but you don't really take in consideration those consequences you sign that form to go away cuts your son throat (Dad gets emotional and cries mum comforts him …………)

Silence…… I ask dad if he ok and if he want to stop (me)

No am ok that the thing when he came back with no trachy and ENT consultant 1 explains his reason why this NPA tube he could get it in so we had a bit of a fall out (laugh dad and mum) you told me yesterday the NPA was the least stable way and the tracheostomy was the only way forward and today and now you tell me NPA best way and the tracheostomy wasn't worth the risk it's the fact that he contradicted himself there but I understood once he explained it that cause the swelling had gone down he looked more stronger lets (Dad)

He wanted to give him a chance before he went ahead with the tracheostomy he wanted to make sure it was the right decision and it turn out it was you know now we know 100% that the tracheostomy is the best thing for him because of what ENT consultant 1 did so were more than happy for him to have this now and that what you no that's he still here now he not ventilated he breathing on his own because of the tracheostomy (Mum)

Mild's more comfortable the difference in him (Dad)

Actually after he had it done he came back from theatre I cried didn't I with relief because he was just alert wide awake and he just looked so much happier it was unbelievable to see the difference in him in those few hours was amazing so so relieved just yeah (huge sigh from Mum)
Silence….

Just thinking about it now you just feel that relief again that he so much happier you just think that little bit of plastic makes that much difference to are little boy's life amazing silence …………………………………………..(Mum)

So how have you managed with the tracheostomy? (me)

Everyone keep telling us we done really well don't they (Mum)

First few days was easy as we didn't have to do anything (Dad)

Yeah that's right (Mum)

You didn't have to clean it had to let it heal and didn't have to change it and didn't have to do a change for a week and then seeing him happy we just sat back and enjoying him and saying oh what bother nothing worry about (Dad)

Yeah (Mum)

Then you turned up with the training package (Laugh) going through that first 3 weeks you just did not have time to think say from DGH 1 to DGH 2 to

here being told this being told that and having Sarah here as well which is a big distraction we are constantly on the go, so it weren't until night time we actually sat down even then even then you weren't thinking u were just thinking about next day having to get up early (Dad)

Going over there find out if he been alright during in the night (Mum)

Yeah it not until his tracheostomy done we sat down and you start thinking about and that's when it actually hits you bringing it home silence………………… support you get from family and friends it got us through the first few weeks didn't it (Dad)

Definitely yeah (Mum)

Silence ………..

Like and when you tell like I know telling my dad that he was going to have his tracheostomy done and my dad was like o right ok straight over his head did not bother him in the slightest so knowing your family that it does not bother them I know it shouldn't but I mean you know you don't know really how people are going to react to that sort of thing do you but knowing it's not going to bother them in the slightest and they're still going to love him like you love him that makes a big difference as well doesn't it (Mum)

Silence………………
This will be the first time I have actually sat down and spoken about it properly is isn't it (Mum)

Silence…………….
It's good isn't it (me)

Frees you up (Mum)

Silence……………………………………………………………….

So home soon how are you feeling about that? (me)

Over the moon a little bit apprehensive that we not going to have that 24 hour support behind us with the nurses and the doctors and everything but (Mum)

I think it's going to bring a sense of reality to it as well though cause when you are here especially with Sarah it's get up say 730 whatever over there by 9 o'clock as his side u do his clean doctors come round nurses come round prodding and poking and then you are cleaning doing his day cares and then its lunch time and then go for lunch come back do his nappy do a fed may speak to another nurse or two and then it's like tea time and then you come back again you don't get any time do you just one on one with him do you or (Dad)

Yeah it's always interrupted isn't it (Mum)

Yeah it been disjointed while your here in a way even now there's no routine in place shall we do this now oh no she wants to do bloods in 5 minutes then it's so to get home and get in your own routine for Sarah to be in her routine will be a good thing as well (Dad)

It's had a massive impact on her as well hasn't it that she has not gone to bed on time so she tired and when she tired she gets grumpy (Mum)

At least when we get home we got family who can take Sarah off for an hour or two or family come round for a cup of tea take a bit of pressure off and ermm and a shop you can all go two rather than have to leave your son behind who you should be showing off in the buggy and things like that the service here has been absolutely phenomenal and we knew before we came

here they gave us a option of here or paediatric hospital 2 we chose here we weren't even aware of MacDonald house or anything like that or (Dad)

We weren't sure what we were going do were we (Mum)

The level of care that is actually provided here but to leave this as said now it's going to be relief cause we fully trained now we just want to take ownership of it now silence………….I do a lot of training at work with regards to insurances or situations you don't use that information on a day to day bases sometimes you might use it once a month once a year but you got to have it therein back of mind so this training the day cares yes that's fine (Dad)

Yes changing his tapes and his stoma (Mum)

Yes that's routine now like going into work and signing in and doing morning checks and things but training as far as resuscitation and things like that that's going be the scary part as it and think you have to keep reading and going over the training package just keep fresh in your mind as the worst thing you want to do is to go into a situation where you are panicking about oh hang on is it this first this first what do you do here make sure you got everything on hand which I said to (mum) each fortnight each month going have to check the emergency bag and check were everything is and check just do the routine checks of stuff we use on a day to day bases training wise its been good enough think we need to take it on board that we need to keep ourselves up to date with the processes hopefully touch wood we will never need them but as say changing everything doing actually daily and weekly checks (Dad)

Yeah let's hope we don't have to do any of that (Mum)

Yeah (Dad)

We go in every morning we get everything ready that we need and we do it ourselves now we don’t even let the staff know that we are doing it do we (Mum)

No (Dad)

We just get on and we do it as we are more than confident in doing stuff like that aren’t we and I think a lot of it is just down to sort of doing it it’s not something that you can learn by watching you have to actually get in and on and do it and (Mum)

That’s where I am slightly different I am more observer mum a doer so she was very keen to get in and do it I prefer to observe something a few times and question then get it into my head I would do it that way this way nothing worse than being put in a situation than seeing it once then hang on what am I best doing now cause there no time for it when you got a screaming child ha ha ermm I prefer to observe it myself and then that’s why I let mum do it first but the only down side to it was once you done one it’s like I want to do that again now but it’s obviously a tracheostomy you can’t change it every 20 minutes (laugh) u can’t ,when I am in work you get told a routine you get told a procedure it’s not until that you won’t get 30 customers in one after the other so you can get so you have to wait for the right time to actually use it that’s the worst part once you done it its like yeah that’s good I want to do it again (Dad)

You sort of find yourself feeling a bit like it’s the adrenaline it must I think you sort of get a bit over excited don’t you that you done it and it went well and everything ok oh yes! right tomorrow tomorrow bring on tomorrow so we can do it again (Mum)

Cause in this environment you don’t really get you don’t really feel like a parent you don’t feel like you’re doing everything cause you got the nurses there who come in who say I have fed him and changed his clothes he was sick with if I was at home I say strange that you changed my child or changed his bottom (Dad)

It’s doing his tapes and not having nurses saying we have done them they been done today or changing his nappy and them saying he had a number 2 or it’s just getting him home and him being are baby silence …and enjoying him (Mum) silence ……………………

Is there anything else you’d like to say? (me)

Er I like to mention I mean how long he had his trachy now (Mum)

5 weeks (Dad)

5 /6 weeks the way he copes with it now already is amazing he will just as soon as you pop that roll under his head and swaddle him up he knows what’s coming and he just lies there and waits for it to happen and he cough a little bit and if we take too long doing something then he gets a bit annoyed with us and he cries but (Mum)

It’s normal for him at this stage in his life (Dad)
Yeah it’s already his routine (mum)

It’s us that have had to adapt to the actual (Dad)

Yeah (Mum)

At the moment as I say (Dad)

That’s always been the way for him hasn’t it were as obviously we’ve had another child but we never had to do tracheostomy cares for another child so it been a bit of a silence……….. (Mum)

If it had been are first child I think it would have been completely different or we feel may been different cause you don't expect cause we had Sarah and everything was ok to have this one now it's it's a different feeling I think we have been a bit more cause not the norm you see everyone else with these perfect children and things it's not the norm to have erm (Dad)

Yeah to have to go through all that feeling yeah it's hard to explain really without sounding a bit shallow (laugh) but ermm I think if Tom had been are first child I don't think I would have wanted to have any more and I just think it's because silence …(Mum)

First thing is like that's its unfair on a child why is it our child or why is it this child what's he done nothing wrong but as adults you got to think is not his fault its nobody's fault it is who it is and as say the way you got to cope with it is it needs to be done he is still your child if somebody give him to you for 2 years it's doing a change every day or once a week it's just its just in the short term he won't he won't remember any of it lucky for him but you got to do what you got to do as say at first was a big punch in the stomach as where is all this coming from we know in the future we going have his heart operation to look forward to mmm erm potential learning difficulties erm these sort of things silence .. You just got to deal with the here and now (Dad)

Yes yes (Mum)

He still our child so (Dad)

He still beautiful and he is still perfect laugh.. he is Tom laugh…
The thing in fact I am going to find a little bit difficult I think about going home is people pitying me because I have got an ill son but he is not ill he just breathes differently you know I think that what I am going to struggle with more than anything is that people might treat us differently now because of it but I sought of

find I get myself a little bit annoyed about it because there is no reason for him to treated differently he is he is still (Mum)

He still perfectly able in every way it's just (Dad)

Yeah he still going to be running around and causing havoc silence …….
He just breathes differently it's not it's not a big deal to us anymore I suppose (Mum)

It no bigger no when you first hear of this tracheostomy you seen pictures of people on TV or this that and the other but once you actually get into it and come to understand it and come comfortable with it and think to be given an actual tracheostomy a couple of days before just to look at and feel and play with and that makes it a bit easier to come to terms with but once seen your child destat down to 50 or 40 or lower going black and blue and two nurses resuscitating him in a way (Dad)

It doesn't matter does it (Mum)

It doesn't matter (Dad)

As long as he is ok it doesn't matter (Mum)

Silence …………………

Sarah been amazing his trachy doesn't bother her in the slightest does it she been looking at all the other pictures of the boys and girls on the ward that have had them (Mum)
It's like my goodness she dress her own dolls up with one we been given (Dad)

We been given her out of date tubes “I want my baby to be like Tom” so we tied it onto her doll and she was over the moon as her baby was like her little brother she absolutely adores him ha laugh (Mum)
Silence ………………………

I think the level of support is actually from other parents in the same situation has been quiet valuable to us as well (Dad)

Yeah (Mum)

Staying here and talking to one parent whose son got the Di George Syndrome another parent whose kid has a VSD in their heart another Kid Whose got learning difficulties they all come together and say oh tell you something no one does else tell you that’s this this and this and this support group and this on the internet you can find so this that and the other so being somewhere like mac house is a great way of (Dad)

We haven’t actually met anyone whose children has had a tracheostomy have we but just the information that they can give you with regards to (Mum)

Di George’s, VSD, DLA forms DWP forms (Dad)

Yeah (Mum)

Family allowances (Dad)

Yeah (mum)

Family ermm support days groups all that sort of thing probably you wouldn’t think about a form but as say being in this environment everyone got something that they can give to you support and they being going through what we being going through months ago years ago (Dad)

Yeah (Mum)

Having same worries so they completely understand and can empathize with us and in the end it's an important part of it as well in the end you don't want sympathy you just what empathy (Dad)

Somebody who understands that (Mum)

They understand rather than just (Dad)

People telling you rather than saying oh am sorry (Mum)

Yeah I was back home at the weekend and friend of mums come to me said sorry to hear about your boy (Mum)

I feel sorry for you having to go through all that (mum and dad together)

Yeah feel sorry for you having to do those changes and things its I like what you sorry for you not been in that situation so how do you know how it feels why not say congratulations first as we had a child (Dad)

A new baby (mum)

Yeah sort thing like we rather than just assuming it must be bad (Dad)

Yeah we are not feeling sorry for ourselves were happy that he is stable and he is happy yet people seem to think that (Mum)

We want sympathy rather than (Dad)

Yeah (Mum)

Rather than just asking about Tom is he putting on weight he is happy does he smile a lot laughs… yeah (Mum)

We haven't put anything on these social media sites so after first couple of days we put a notification up saying this were we are at don't want any panic (Dad)

Thank you for everyone who has asked how he is and (Mum)

This is the situation were in and can you please respect are privacy at this time and then you get well-wishers and now you got people putting things up like please share this if you got someone with a physical disability it's not it's just like (Dad)

Yeah they just assume that (Mum)

That's being supportive in some way but its (Dad)

It's the opposite really it's a bit sort of like oh there nothing wrong with him it's not its quiet hard to (Mum)

It's not scary his physical appearance and that's not what we are looking for so say he a normal child as said from start it's like a dummy but in a different place so take it out clean the dummy and put it back in as say again speaking to people downstairs we are extremely lucky that he got only what he has got some other parents have gone through a hell of a lot more with different ailments people with brain damage kids and people with actual erm actually physical disabilities and incurable heart problems lung problems (Dad)

People whose children can't leave the hospital because they are ventilated constantly or they need that higher level of care that they can't get at home but I don't (mum)

But what seems to us so huge at the start but when you put into context it’s just another why for him to breathe which is stabilizes him which we grateful for (Dad)

Mmm (Mum)

Fingers crossed it’s only for a short time so (Dad)

I don’t find myself feeling sorry for those parents who do all that sort of thing I totally respect the fact that they just get on and they do it and will do actually anything for their child and I feel quite sort of proud of myself that I can it doesn’t matter we will do that for are little boy cause that what he needs and that’s it am not going sit around thinking oh why you know you do sort of think at the start why are we going through this (mum)

What have I done wrong (Dad)

Why us but when and I think now it’s just a case of it doesn’t matter why he is happy he is alive you know it doesn’t matter (big sigh from mum)
Silence …………………………………

Just keep finding myself thinking he is Tom regardless of anything he is Tom and we love him (mum)

A stroppy little sod isn’t he (Dad)

Yes he got a right temper on him (mum)

Yeah (Dad)

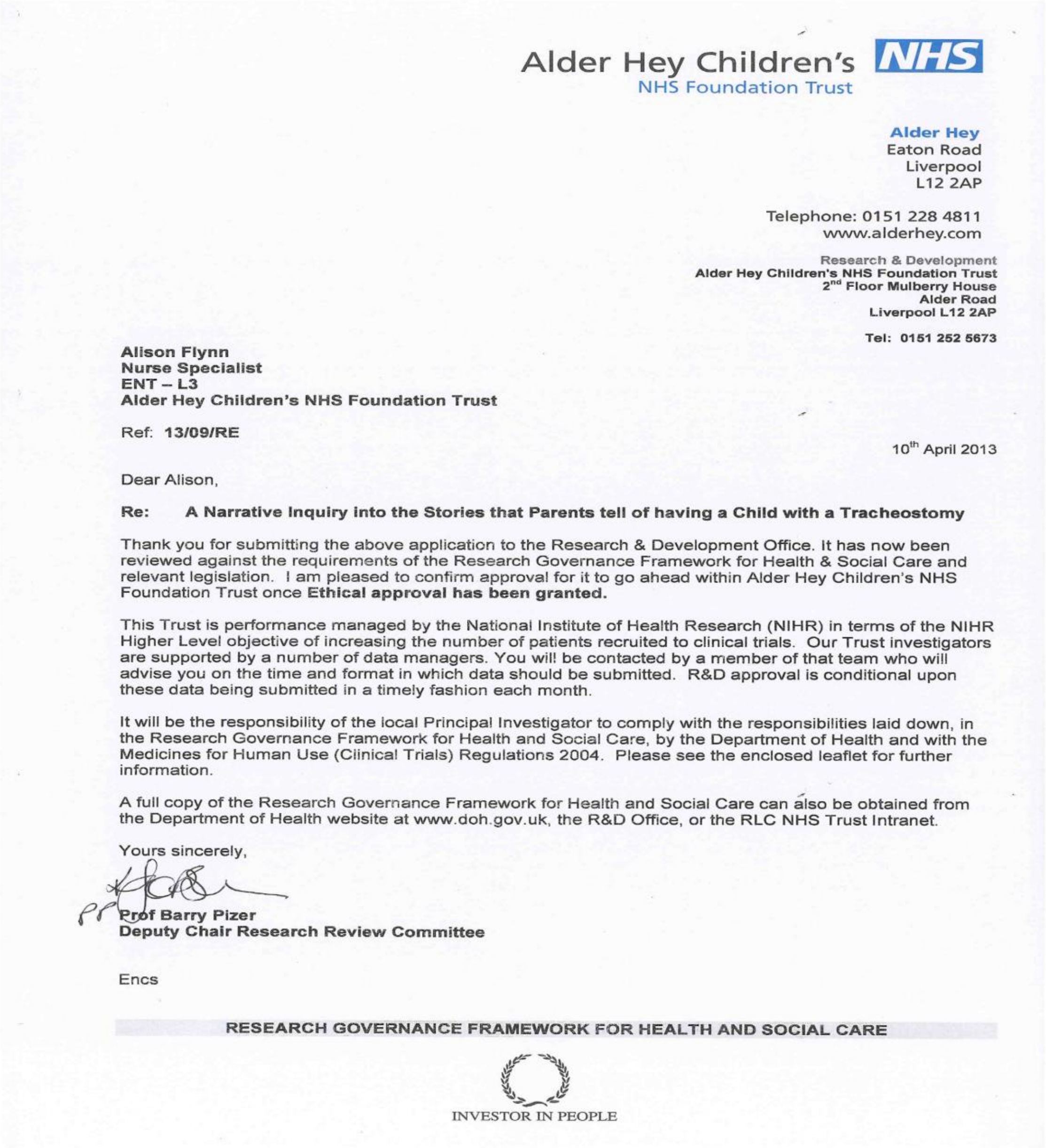
But we love him the same regardless of his tracheostomy where he had it or he doesn’t have it its Tom (mum)

Silence ……………………………………

Sorry for rabbiting on there (mum)

No thank you very very much (me)

Appendix 7: Ethical approval – from Alder Hey Children's Foundation Trust.



Alder Hey Children's **NHS**
NHS Foundation Trust

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Telephone: 0151 228 4811
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Alison Flynn
Nurse Specialist
ENT – L3
Alder Hey Children's NHS Foundation Trust

Ref: **13/09/RE**

10th April 2013

Dear Alison,

Re: A Narrative Inquiry into the Stories that Parents tell of having a Child with a Tracheostomy

Thank you for submitting the above application to the Research & Development Office. It has now been reviewed against the requirements of the Research Governance Framework for Health & Social Care and relevant legislation. I am pleased to confirm approval for it to go ahead within Alder Hey Children's NHS Foundation Trust once **Ethical approval has been granted.**

This Trust is performance managed by the National Institute of Health Research (NIHR) in terms of the NIHR Higher Level objective of increasing the number of patients recruited to clinical trials. Our Trust investigators are supported by a number of data managers. You will be contacted by a member of that team who will advise you on the time and format in which data should be submitted. R&D approval is conditional upon these data being submitted in a timely fashion each month.

It will be the responsibility of the local Principal Investigator to comply with the responsibilities laid down, in the Research Governance Framework for Health and Social Care, by the Department of Health and with the Medicines for Human Use (Clinical Trials) Regulations 2004. Please see the enclosed leaflet for further information.

A full copy of the Research Governance Framework for Health and Social Care can also be obtained from the Department of Health website at www.doh.gov.uk, the R&D Office, or the RLC NHS Trust Intranet.

Yours sincerely,

pp **Prof Barry Pizer**
Deputy Chair Research Review Committee

Encs

RESEARCH GOVERNANCE FRAMEWORK FOR HEALTH AND SOCIAL CARE

INVESTOR IN PEOPLE

Appendix 8: National Ethics Service (NRES)

NHS
Health Research Authority

12 July 2013

Ms Alison Patricia Flynn
Alder Hey Children's Foundation Trust
Eaton Road
West Derby
L12 2AP

Dear Ms Flynn

Study title:	**A Narrative Inquiry into the Stories Parents tell of caring for a Child with a Tracheostomy**
REC reference:	**13/NW/0349**
IRAS project ID:	**120442**

Thank you for your letter of 04 June 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.
The further information has been considered on behalf of the Committee by the Chair and Dr Edwards.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Helen Penistone, nrescommittee.northwest-liverpooleast@nhs.net.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below). A Research Ethics Committee established by the Health Research Authority

Conditions of the favourable opinion

The favourable opinion is subject to the to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter	from Alison Flynn	16 April 2013
Interview Schedules/Topic Guides	1	01 April 2013
Investigator CV	Professor Bernie Carter	15 April 2013
Investigator CV	Alison Patricia Flynn	
Investigator CV	Adam Jan Donne	01 March 2012
Letter from Sponsor	from professor Barry Pizer	10 April 2013
Other: Signature page		01 May 2013
Other: IRAS signatures		07 May 2013
Other: Contact sheet for parents	1	01 May 2013
Participant Consent Form	2	01 May 2013
Participant Information Sheet	2	01 May 2013
Protocol	1	01 January 2013
REC application	120442/441229/1/410	25 April 2013
Response to Request for Further Information	from Alison Flynn	04 June 2013

Appendix 9: Building, Sport, Health (BUSH, 151) Ethics Committee University of Central Lancshire

21st February 2013

Bernie Carter & Alison Flynn
School of Health
University of Central Lancashire

Dear Bernie & Alison

Re: BuSH Ethics Committee Application

Unique Reference Number: BuSH 151

On the basis of the information contained in the Research Degrees Application form, the BuSH ethics committee does not envisage any insoluble ethical issues arising that might make the proposed project non-viable for MPhil/PhD. The committee therefore has no objection to the project ‘A Narrative Inquiry into the Stories that Parents tell of having a Child with a Tracheostomy.’ proceeding to registration.

However, before any data collection from research participants commences, a full proposal application will need to be submitted to and approved by BuSH Ethics committee. When you make this application, please ensure that you quote the unique reference number (above) on your application form.

You may find it convenient to make separate proposal applications for different stages of the project, especially if the design of the later stages is highly dependent on the findings from the earlier stages.

Yours sincerely

Denise Forshaw
Chair
BuSH Ethics Committee

Appendix 10: Research consent form

Consent form to participate in interviews: Parent/Carer

A Narrative Inquiry into Stories Parents tell of having a Child with a Tracheostomy

Name of Researcher: Alison Flynn

Supervisory Team: Bernie Carter, Lucy Bray and Adam Donne

Please initial box

I confirm that I have read and understand the Information Sheet for the above study and have had the opportunity to ask questions and had these answered satisfactorily. ☐

I understand that I am able to withdraw from the study at any stage during the twelve month period ☐

I understand the interviews I take part in will form part of the data collection for this study. ☐

I understand that the interview will be audio recorded with my permission and that some of the things I say in the interview may be quoted in the final report or any publications and I understand that these will be anonymised. ☐

I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the records. ☐

I agree to be contacted for a follow up interview. My preferred contact details are ☐

……………………………………………………………………….

I understand that the research will not be completed until 2017 and I agree that the researcher can send me the results of the study ☐

I agree to take part in the study. ☐

Name of Participant **Date** **Signature**

Name of Researcher **Date** **Signature**

Appendix 11: Questions of story telling practice (from Frank, 2010)

Greene family Time point 1 interview

Socio-narratology questions

1. What makes the story narratable?

Tom's birth's /struggle for survival

From unpredictable chaotic events /bravery/ to eventually finding the right balance within their lives as Tom's parents

Stories of different places and times /moments of fear/ worry/ upset/ relief /

Stories of different parenthood /commitment / a child's life in danger / hope /togetherness

Inspirational stories / of sadness that lead to acceptance moving on stories

2. Who holds their own

Tom as he has a threat hanging over him /his survival

Parents as they face difficult/difference parenting challenges but strive to move their life forward

3. Other who hold their own

ENT consultant 1 – trying to give Tom a chance / helping to guide parents / trachy last resort

Sibling (Sarah) – her routine/life changes

3. Forces of fear

The tracheostomy / difference disability / risk/ consequences/threats

ICU

Operation risks /consent

Receiving complex diagnosis

Internet

Seeing your child struggle to breathe /unhappy/ hoping he be ok

Prejudice/ perceived prejudice from society

People reactions / lack of understanding

4. Forces of desire

Grateful /relief

Getting the right help

Parenting role / even in a different way

No worries

Love

Toms a child first and foremost

Home

It’s a short term trachy

5. Effect of being caught up in their own story

People on social media get out of control

People reactions –empathy not sympathy

Routine disruption – changes for the family

Nursing staff looking after your child / you’re the parent

ENT consultant 1 caught up in his own story /wanting the trachy to be a last resort

6. Work of memory

Go back to having their first child –difference tom doesn't deserve this no child does

Good to chat brings relief thinking back frees you up .

Tom will have no memory of it / easier for parents to remember

The trachy in the short term / makes it easier

Talking to other parents about their experiences comfort to share their memory's /supportive

7. **What's at stake?**

Tom's life and being a child with a trachy getting past this

8. How is the stake redefined?

Realization that a trachy keeps tom alive brings a future for tom and the family

9. How does the story help parents remember who they are?

DAD compares things to do with the trachy to his every day working life he is proud he can achieve looking after his son in this way **Mum** frees herself up by taking feels that relief again when she realises that her son having a trachy has changed there situation for the better/ remember they can now be parents

10 Has it changed possibilities?

Tom has a future / go home / eventually be a family

Smith family Time point 1 interview

1. What makes the story narratable?

Life changing experience for rose and family that’s emotional/scary but becomes easier

No choice story

Face your fear as a parent story

Accept the card our dealt /deal with what life throws at you

Family stories

2. **Who holds their own?**

Rose to survive –gone through so much

Family – waiting/wanting for Rose to come home /

Protection

Other that holds their own –

3. Forces of fear

Seeing our child go through so much /illness/operations

Shock of a tracheostomy

Other medical problems

People reactions –identity

Being on a vent /icu

Changing the trachy tube

4. Forces of desire

Normal parent ng/ child /family

Home /family support

Seeing her develop well /breathe easier

5. Effect of being caught up in the story

Brought out emotional build up from mum that surprised her

Impact on the family

Why our child

Very stressful

No choice for parents

6. Work of memory

Reflect on other children which led mum to think why Rose?

Thinking back to what her daughter has already been through

Thinking back to when she carried rose for 9 months

Reflecting that's its short term seems to make it easier

7. What's at stake?

Rose's life with and needing a trachy and the impact on the family

8. How is the stake redefined

Its changed Rose's life and its brings a future

9 How does the story help mum remember who they are ?

She has her baby and can think about what had been at stake and know what rose and the family have been through

10. Has it changed possibilities? Rose is off a vent/ on the road to recovery /has a future