

The family centred experiences of siblings in the context of
cystic fibrosis: A dramaturgical exploration

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This thesis is submitted to Cardiff University in fulfilment of the
degree

Doctor of Philosophy

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ABSTRACT

The aim of this thesis is to explore the experiences of siblings within their family, who are living with a child with a life limiting chronic illness. Siblings have been identified as being a marginalized group because there is limited recognition of their sibling voice within the literature and in family centered care practices. Family centred care is an important aspect of children's nursing in terms of inclusivity and maintaining dignity and respect of the whole family and needs to include the sibling. Therefore specific insight into their worlds is presented to inform care because siblings do need help when journeying along the cystic fibrosis trajectory with a brother/sister.

A qualitative methodological narrative inquiry has been elicited to engage siblings within the context of their family with the use of a bricolage of creative participatory methods (n=10 children in middle childhood living with a brother/sister with cystic fibrosis). Narrative interviews, observations and the use of visual media have provided the platform for the siblings expression of their performed voice that was encapsulated in the collection of over 200,000 words of data, along with pictures, poems, songs and artifacts.

Goffman's theoretical framework of dramaturgy was used as the exploratory 'lens' in which to view the sibling's front stage, back stage and centre stage stances. Microsoft word was used to conduct a thematic analysis of the data collected (observations, interviews and visual media), which provided an insight into sibling position, space, roles encompassed in their overall self-presentation in their familial/cultural milieu. Data analysis is presented as a three-act play called "The segments of the sibling mosaic" where the siblings are performing on the stage set of family life within their home. Through interactive performances siblings act out scenes of multiple presentations of self to reveal the contradiction

between their ideology and reality of their lives as a consequence of the opposing force of cystic fibrosis.

Through the use of Goffman's framework I suggest that the children's expression of voice goes beyond the use of the spoken word, as siblings gave voice through their constructed and co-constructed performances. I also suggest that siblings are skilful in their interactions as they are able to fluctuate easily between their dramaturgic front stage and back stage stances. I argue that siblings are placed in a decentralized position in family life and I introduce three prominent positions/spaces where these children stage themselves, which are "in the wings", "left of centre" and in the "off stage place sets". I highlight how siblings demonstrate diplomacy and wisdom in their communicative interactions of being good so as to remain protective, loyal and maintain family equilibrium. I argue that siblings should not be labeled or referred to as being well or healthy in the absence of physiological illness, because they provide an insight into their emotional self where a need for help is identified.

Bringing siblings to centre stage and using creativity in this study has identified one way of helping them to share their experiences and enabling their voice to be heard to inform future aspects of care. However, further research is suggested.

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“Imagination is the only weapon in the war against reality”

Alice in Wonderland

Lewis Carroll

1. CHAPTER ONE

1.1 INTRODUCTION

Section 1

“It’s the end where I begin”

As a reader of this thesis entering this introductory chapter, this is probably the beginning of your journey into my study that is focused on exploring the experiences of siblings living with a brother and or sister with the chronic disease of cystic fibrosis. For me as the writer, I am just reaching the end of this piece of work having engaged in more than four years of study in conducting my research as a part-time PhD student while working full-time. During this period I have been on an expedition that has led me along many paths that have enabled me to be transported into the temporal worlds of children and their families to bring me full circle in presenting this work.

By beginning at the end I am able to prepare you for the creatively presented storied worlds of siblings that lie ahead, because this work is imaginative and perhaps challenges the boundaries of presenting a thesis in the traditional sense, because it is presented in the form of a play. A play where children are viewed as social actors, who actively and passively engage/interact in scenes that demonstrate their performance, their voice, and their experienced worlds when living with a brother and/or sister with cystic fibrosis. In their dramas children use arts, crafts, artefacts, poems, psalms and songs to creatively express their presentation of self to achieve a given impression (Goffman1959). Meaningful symbolic quotes from children’s literature are used at the beginning of each chapter. The specific scenes, acts and behind the scenes preparations will be outlined later in this work.

1.2 LITERARY AND DRAMA EXPLORATIONS

By beginning at the end I can tell you of my fascination and interest in listening to, reading and watching many fictional and non-fictional siblings’

stories whilst moving along in my research journey. I have listened to audio book stories such as *Crow Lake* by Mary Lawson (2002) - a fictional account of a girl called Kate who is orphaned when her parents are killed in a car crash and she and her siblings are left to be looked after by her older brother. Kate reflects back on her childhood experiences with her siblings as an adult to recognise she cannot escape the childhood family ties of the past.

I have watched poignant movies such as *Melancholia* a Danish award winning drama /Art film directed by Lars Von Trier. A film about the trying relationship of two sisters and how one sisters' deteriorating mental health reawakens, as she gains a new strength and spirituality to support her older sibling as they sit in their wood built cave with her nephew when the collision of melancholia with the earth ends the world to bring a sense of peace. I have also watched documentaries, which have included *Dying to Live*, the true story of twin sisters Kris and Maren, age 23 years old. Kris was diagnosed with terminal breast cancer at this young age and the documentary talks about their difficult experience and their strength to launch their campaign "coppafeel" to encourage young women to check their breasts for lumps. I have also engaged with observe the interactions of sibling relationships in reality programmes including the *Kardashians*, a family with several siblings that encounter relationship challenges including coming to terms with their father being transgender.

It was not only sibling stories that I explored but also those focusing on children and aspects of childhood. One particular fictional girl stood out from one of the audio books that I listened to and that was the narration by Ruby from the book called "The quality of silence" by the author Rosamund Lupton (2015), as she spoke with clarity and determination. The narrator presented Ruby as a 10-year-old deaf girl who relies on creativity to express herself in her world. On her journey to look for her father in Alaska she talks about her blog that she calls "words without sounds" where she uses other senses to describe a word rather than

saying the word itself. For example you pick a word and then describe it as how it feels, how it tastes and how it smells. I quickly associated with her creativity and found myself homing into my own inner child (something I never lost being a qualified children's nurse) to join in the game and I thought of how I would describe my own name and persona if I were engaging with a child like Ruby. "Amie", I thought, I would place a marshmallow in the child's hand and get them to squeeze it. "Amie" the word, feels like a soft marshmallow, pressed down for the "A" and allows the marshmallow to spring up to emphasise the "mie". Placed in your mouth it is a word that would melt and taste like chocolate, it would smell like freshly baked warm bread and of course the name means friend.

Being aware of self in different ways was important for this study because it was crucial to connect with the children, to be creative and be aware that some words do not have sounds for children even when they are not audio impaired. For some children they do not have the words because they do not have the vocabulary or know how to express themselves through voice and so they use other means. Being able to use such adaptation was important and necessary when working with the participants in this study as it enabled my connection and understanding of their worlds so that they could be encouraged to express themselves in an appropriate way for them.

Alongside reading the academic literature I considered my experience of my alternative exploration of the above to be part of my immersion in gaining insight and understanding into sibling and childhood worlds in terms of exploring ideology, fantasy and reality, as well as enhancing my own writing, listening and observation skills.

In considering the fictional and non-fictional stories above as well as the available evidence that I had explored in the literature, I was able to enter the field for the purpose of my research to experience the 'real' lived worlds of siblings with their families that participated in this study. What I

also took with me was my own experience that enabled me to engage easily with the children in their home settings.

1.3 PRESENTING AN AUTOBIOGRAPHICAL ACCOUNT

Below I have provided an autobiographical positional narrative, which will enable the reader to have greater insight into my motivation and prior experiences in commencing this study. Providing an autobiographical account is useful as it can enable the self-governing of the researcher. It provides insight into coming to know oneself through gaining understanding of prior experience and its influence on ones own value, beliefs and decisions (Watts 2009). It can also provide insight into the interconnectedness of the researcher and the researched (Hollway and Jefferson 2007). Mentioning my prior experience is important because it sets my own positioning of self within this thesis, which is an essential according to Minglers (2003) and Durant-Law (2005).

1.4 MY POSITIONAL NARRATIVE

As I sat in the back seat of the black car I could see my sister looking at me from the car in front. She had short brown hair that softly framed her square shaped face, her skin looked clear, glowing and fresh with the lightly applied make up adding to the glow and lightening up her smile. Yes, she was smiling, but I was not. I was dazed but continued to look at her as our eyes met, we were connected with a mutual knowing.

Either side of me on the back seat were my two nieces, one with shoulder length blonde hair and one with shoulder length dark hair. They were looking ahead like me. The three of us looking forward but at that moment none of us spoke a word. I eventually looked away from my sister and focused on my nieces as I gazed at each one individually, I observed their faces and I could see two beautiful young girls, my sister's children who I was so proud of. I was proud of her for having them, as they were not only my nieces but also my godchildren. I could feel their warmth as they sat either side of me but also their chill and I felt sad for them in that moment.

I was holding their hands tightly, our fingers were entwined, cool and clammy, neither one of her children were letting go, and I was not letting go either as I knew that my sister would not want me to. The three of us sat there, we all remained connected physically and emotionally. As I looked down at their hands I could see the silver charm bracelets that surrounded their wrists. On each bracelet was attached a silver star that I had bought them. The star was a symbolic representation of my sister who looked on from the car in front, now forever smiling. It was symbolic of the star I named after her and gave to her as a gift, a gift she was delighted with. I looked at the star on each of my niece's wrists and then at each of the girls again and then back to my sister. It was a surreal moment and a life changing one. Nothing or nobody could ever have prepared me for that day, because that was the day I lost my sister, the day I said goodbye. Sitting in that car I continued to look at the photograph that was faced towards me from the car in front. It was a large photograph that she had chosen to be in the back of her car on the day of her funeral. My sister was five years older than me and she died of lung cancer seven years ago.

It was not until she passed that I really thought about our relationship or reflected back on our childhood experiences that we had together.

My sister was five years old when I met her, she had already had experience of living in the world and I always looked up to her because she was older than me. I mean a five-year age gap as a child felt like a lot it and it was in terms of our developmental and socialisation skills.

I remember as a child we would sometimes play games together like being in the army. We would be in the school playground and my sister would always be the sergeant major and I would be the soldier. She would put me through my paces by getting me to march, here, there and everywhere as well as making sure I would stand to attention. Sometimes we would

play “dress up” and play “house” and again my sister would have to be the boss, she would be the parent and I would be the child. Sometimes we would run free and play in the fields together and then go blackberry picking, but she would always say where we could and could not go.

Despite wanting to be in charge and be the boss when we played games, she could be quite nervous as times. This meant a bit of role reversal because she was always scared to go upstairs on her own and she did not like the dark, so I would have to go upstairs with her. I remember having to sit on the top stair outside the bathroom when she was having a bath because she did not want to be on her own. So I would be her protector at times. She seemed to be more dependent on me, than me on her and that was reflected in my parent’s words of “look after your sister”. I never heard them say that to her. Perhaps it was because they noticed an independent me.

When my sister started secondary school she did not want to play as much as she had new friends and it did not look cool having a baby sister hanging around. Her interests changed and she was more into her music and she would go into town to hang out with her peers and she had made friends with a new girl who lived across the road. They were the same age, so they would always be together and I had my own best friend who lived a few doors away.

I guess I had probably not consciously reflected back upon these childhood times, because I was just getting on with living my daily life. I had a taken for granted notion that my sister would always be there, but now she was not.

I remember along time ago when we had the conversation where she spoke of “if anything happens to me” and my response was “don’t talk like that, I will go before you”. I think my sister was being practical in wanting to have that conversation especially with having the children, whereas I

had wanted to avoid such talk as I did not want to think about her absence in my life.

If anything I had always expected to go before her because I had always been the sickly one, enduring many hospital admissions for most of my childhood, well from birth until I was 13. I was born with hirschprung's disease (a disease that effects the nerve endings in the bowel) and then had recurrent bowel, bladder and kidney problems requiring much medical and surgical intervention with my last surgery being age 13 when I had my kidney removed.

My sister and I would be separated in those times of my hospitalisation. We were also separated for a time when my parents split up when I was 10 and she was 15. I never really thought about or talked about how those moments of separation or my being ill had impacted on her and she never mentioned it either. My going into hospital became a normal part of our lives. The longest time I was away was 3 months and the shortest time was two weeks. When I was home from hospital, life just went on and it seemed insignificant to mention, as I was not one to dwell on the past and I always strived to enjoy my health, the freedom it gave me, I focused on moving forward and moving away. For my sister she had moved forward too, as she became a wife and a mother, she remained in our hometown. Our childhood experiences had faded into the past as we both embarked upon different life path journeys.

For me it was a career journey. For as long as I can remember I wanted to be a children's nurse and focus on working with children and their families and it was a goal that I achieved. For my sister she worked hard at bringing up a family as well as being a supervisor in homeware retail stores. You could say that my career choice was influenced by those early childhood experiences of hospitalisation and a wanting to give back in helping and caring for others like I had been cared for during some very sick times. Educationally, I missed a lot of school due to recurrent illness, I

was given schoolwork in hospital though, but there was never any pressure to complete what was given. More like, "Just do what you feel up to doing". I was home schooled for a year where a tutor came to the house three times a week for half a day. Eventually I did go back to school after begging my mum to let me go because I felt well. I just wanted to get back to normal and when I was at school I really enjoyed the social environment and being with friends. For my sister, she hated school and could not wait to leave. She hated being in the classroom and was one of those kids that would sneak off and have a cigarette behind the bike sheds rather than going to class if she could. I smile as I think of her doing that, I guess it was her way of rebelling. I remember when she left school at 16 she started work the following week and she loved it. Her job was packing medications for a pharmaceutical company.

For me my journey was different, my education was important, you could say it was my survival as it gave me focus and distraction from being ill. I was never pressured by the teachers to achieve, I think they looked at my pale looking face with sunken dark eyes and thought, "It doesn't matter, she's sick". Even when I was well I was still labelled as "sick" or "fragile". You could say that my rebellion was to prove them wrong, to show them that I could achieve despite missing so much school, being ill and not being ill. Sometimes I felt like the teachers had written me off but I had not. I set my personal goal and that was to be a nurse and I worked towards that. As a child sometimes I would struggle with my concentration and processing of information and quite often I would feel my way around topic areas, sometimes it would take me longer than my peers to understand concepts, but I always got there because I had an inner determination, strength and motivation. I was not one to give up and I would find creative ways to help me in my path. It was not until I commenced my PhD that I realised why I experienced this struggle. As it was then that I was finally diagnosed with dyslexia, something that had not been undetected previously throughout my educational journey. This was finally a relief and it explained a lot.

By the time of this diagnosis I had succeeded in my career goal to become a nurse, where I eventually set up and led a children's respiratory service. I specialised in caring for children with respiratory health problems along with their families over a period of 10 years. I had gained my primary degree, my Masters degree and a PGCE and had taken up a career as a lecturer teaching children's nurses at undergraduate and postgraduate level. In teaching I was still making a difference to children, young people and families through the education of the students. My focus topics of interest for teaching are children's respiratory health as well as family centred care, amongst other childhood topic areas. Yet for me there was still more to be done to make a difference. As a result of my educational journey I developed my curiosity for further knowledge, an inquisitive nature to question practice and identified gaps in care and in the literature. My educational journey has brought me to this point in raising the questions for further study and embarking upon a research journey. Although on reflection it was not just an educational journey, but also a personal one. It is framed by my prior experiences, in being a sister, in being unwell and being well, in being a nurse and caring for children and their families, in having an interest in childhood respiratory illness/health and in being a teacher. In some ways I feel like I have come full circle in reaching this point and in some ways I feel like the tables have turned in being a sibling of a sister with an illness, although my experience was as an adult, not as a child.

For me my journey continues, but for my sister her journey was cut short. She is not here, yet she is ever present because we have a "sibling bond" (Bank and Kahn 1982). My sister was older than me, but profoundly, now I am older than her.

In presenting this positional narrative it would not have seemed right to present a thesis focusing on siblings without mentioning my own.

“From the moment I fell down this rabbit hole, I’ve been told where I must go and who I must be. I’ve been shrunk, stretched, scratched and stuffed into a teapot. I have been accused of being Alice and of not being Alice but this is my dream and I will decide where it goes from here.”

Alice Kingsley
Alice in Wonderland.
Lewis Carroll

SECTION 2

BACKGROUND: LAYING THE FOUNDATIONS:

To enable greater understanding of the disease of cystic fibrosis, its treatments, its context in relation to this study and family life, background information is provided here.

There is a focus on considerations in relation to the genetic condition cystic fibrosis (CF), the disease process and its impact in terms of the altered physiology that occurs is discussed as well as current treatments and contemporary advances in care being outlined. Following this discussion, key theoretical concepts will also be explored to add to the foundations of the study.

1.5 CYSTIC FIBROSIS

1.5.1 WHAT IS CYSTIC FIBROSIS?

Cystic fibrosis is an inherited autosomal recessive genetic condition that can affect 1 in 2,500 live births in the UK and 100,000 live births globally (Wiehe and Arndt 2010, Havermans 2011, Mcullough and Price 2011, Cystic Fibrosis Foundation 2015). It predominantly affects white Caucasian populations, but it can also occur in other ethnic populations. If both parents have the faulty gene there is a one in four chance of conceiving a child with CF (Havermans 2011, Mcullough and Price 2011, Wiehe and Arndt 2010).

Historically it was recognised as a childhood disease, but with advances in newborn screening, the use of the gold standard diagnostic sweat test, early diagnosis, treatments and technology, the life expectancy now reaches beyond the childhood years with the median predicted rate of survival being 41 years old in 2015 (Cystic Fibrosis Trust 2015). However the disease is complex and multifaceted so can affect people in a multitude of ways hence the age of death can differ from the predicted survival rate. According to Kuk and Cousar (2015) statistics for the

average age of death from the disease in 2013 was 28 years old. However the Cystic Fibrosis Trust (2015), add that if a child was born with CF today, then their predicted rate of survival would be longer than the current median age of 41.

According to Kuk and Cousar (2015 p1)

“Cystic fibrosis is caused by mutations in the CF transmembrane conductance regulator CFTR gene which encodes the CFTR protein an adenosine triphosphate binding chloride anion channel that functions at the epithelial cell membrane.”

Two mutated copies of the CFTR gene are inherited and they can either be homozygous, meaning they are both the same, or heterozygous, meaning they are both different (CF centre Stanford 2015).

There are 2000 CFTR mutations that have been identified and it is these mutations that are responsible for the dysfunction in the protein production that regulates salt and water transportation within mucous membrane lined organs causing mucous within the body to thicken and prevent the removal/ clearance of secretions (Kuk and Cousar 2015 and NICE 2015). This leads to the increased risk of respiratory infection, malabsorption and intestinal obstruction because the disease affects many organs, including the digestive system, the liver, endocrine and reproductive system as well as the respiratory system (McCollough and Price 2011, Barker et al. 2011, Kuk and Cousar 2015). Kuk and Cousar (2015) suggest that this bodily dysfunction occurs where tissues become inflamed or destroyed.

1.5.2 RESPIRATORY INFECTION

A problematic respiratory infection that can occur in children with CF is pseudomonas aeruginosa, which can colonise the airways of the lungs. This is a gram-negative bacteria which can be very difficult to treat and can be detrimental to the pre existing condition of CF (Normura 2014). Contracting such an infection can influence the prediction of survival of an

individual (Balfour- Lynn and Elborn 2007p139). It can lead to poor morbidity and increased mortality rates and it can be resistant to the regular intravenous antibiotic therapy leaving some patients colonised with the bacteria for their lifetime (Nomura 2014, Folkesson et al. 2012). Whilst there has been a decrease in patients with CF contracting *Pseudomonas aeruginosa* between 2008 and 2013 (CF registry 2014), it still remains a significant problem. Children with CF are also susceptible to contracting other detrimental bacterial respiratory infections too, including *Burkholderia Cepacia*, *staphylococcus aureus* and *haemophilis influenzae* (Balfour-Lynn and Elborn 2007). Therefore it is important that patients with CF do not mix in order to prevent the risk of cross infection. This can be problematic when there are two siblings or more with CF in the same family (Wahab et al. 2014).

Further complications can also occur as the disease progresses in the CF trajectory which can include nasal polyps, sinus disease, asthma, liver disease, kidney failure, depression, atypical mycobacteria, CF related diabetes as well as the need for transplant of the lung, heart and lung or liver (UK Cystic Fibrosis registry 2014). Therefore CF is a life limiting chronic illness for which there is still no known cure, so symptom control with daily treatment and monitoring is essential. As the disease impacts on the bodily systems mentioned above, symptoms can present in relation to those systems and are listed to include, coughing, difficulty breathing, wheezing, changes in sputum colour, production of viscous sputum, weight loss or poor weight gain and growth, malaise, fatigue, diarrhoea, foul smelling fatty stools, salty sweat and dehydration as well as noticeable finger clubbing (Hodson, Geddes and Bush 2007, McColley et al. 2012, cysticfibrosis.org.uk 2015).

1.5.3 CYSTIC FIBROSIS TREATMENTS TO MAINTAIN QUALITY OF LIFE

The key purpose of care for the child with CF is to maintain their nutritional status as well as a healthy lung function in order to minimise the symptoms mentioned above. This can be achieved through several

treatment interventions including physiotherapy, extensive medication regimes, and an increased calorie intake (See table 1 below) (Barker et al. 2011, Williams et al. 2009, Foster et al. 2001, Hodson, Geddes and Bush 2007).

Table 1 represents some of the key treatments for CF. Adapted from information in Hodson, Geddes and Bush (2007) www.nhs.uk 2015 and (accessed 20/10/15)

Treatment and route	Rationale for treatment
Antibiotics (oral/ intravenous/nebulised)	Treatment of respiratory infection
Pulmozyme (DNase) /Enzyme/ nebuliser	Mucous clearance/ reduces viscosity of mucous
Hypertonic saline / Nebuliser	Mucous clearance (may be used if Pulmozyme is not effective or available)
Insulin/ via injection	Stabilise blood sugar levels if diagnosed with CF-related diabetes
Biphosphonates	Maintain bone density and prevent fractures
Corticosteroids	Reduce airway inflammation/ improve lung function. May also be used to treat nasal polyps
Bronchodilators	Treatment of Asthma, wheeze, bronchoconstriction
Digestive Enzymes (Granules/ capsules) e.g Creon to help digest fats and proteins.	Maintain nutrition/ absorb/digest nutrients (high calorie diet, increased fat and protein)
Vitamins A, D, E and K	Nutritional support
Physiotherapy / exercise Active cycle of breathing/ use of mucus clearing devices	Maintain respiratory health, lung function and mucous clearance.

Oxygen	Maintain oxygen saturations if there is poor respiratory function. May need continuous oxygen and more intensive therapy if a lung transplant is needed

There are also some recent advances in available treatments and knowing one's genotype is important as highlighted in the discussion below.

1.5.4 RECENT ADVANCES: THE IMPORTANCE OF KNOWING ONE'S GENOTYPE.

There are two seminal articles that discuss the discovery of the CFTR gene 26 years ago (Rommens et al. 1989, Kerem et al. 1989). It was hoped that the discovery of the gene and the specific gene mutations would lead to a cure and a clearer diagnostic picture for CF, but unfortunately this has not been the case (Wallis 2007). Wallis (2007) adds that the disease has become much more confusing, particularly as there are greater presentations of unusual cases. The most common genotype mutation that affects people with CF in the UK is DF508. It is named as such because phenylalanine a amino acid, is missing from position 508 of the gene mutation. DF508 is otherwise known as the F508 DEL or its new name p.Phe508del (Phe representing the missing phenylalanine). Less common is the G551D (new name p.Gly551Asp) mutation which affects 6% of people with the disease (UK Cystic Fibrosis Registry 2014).

The CF Trust (2015) are currently advocating that patients with CF should know what their genotype is, so that they can access the most appropriate recent advances in treatment. This is particularly relevant in terms of a new medication called Ivacaftor or its trade name Kalydeco as this is a beneficial treatment known as a CFTR potentiator. This improves the functioning of the protein made by the CFTR gene to restore chloride channel activity (Rowe and Verkman 2013). It can be used specifically for genotype G551D and other less common identified genotypes, which

include “G1244E, G1349D, G178R, S1251N, S1255P, S549N, or S549R” (Vertex Pharmaceuticals 2015).

This medication was approved for children age 6 and above in December of 2014 and approved for use in the rare specific genotypes in 2012. However, unfortunately it is not suitable for the population with the more common DF508 gene (Flume et al. 2012). This has resulted in further clinical trials of combination treatments of Ivacaftor (the CFTR ‘potentiator’ and Lumacaftor a CFTR ‘corrector’ which targets the f508 cellular misprocessing (Rowe and Verkman 2013)) in patients with cystic fibrosis who are over the age of 12 who have the Homozygous p.Phe508 del gene. This clinical trial of 1108 patients demonstrated some benefits in the lung function of these patients as well as a reduction in chest infections and damage to the patient’s lungs, which has resulted in a reduction in hospital admissions (Wainwright 2015, The CF Trust 2015).

Following identification of the positive benefit of this combination therapy for patients with the homozygous p. Phe508del (Wainwright et al. 2015), this treatment now has the trade name Orkambi has gained FDA approval in the U.S and is currently under review in the NHS in the UK. Whilst this medication is not a cure for CF, it does have the potential to make a difference to the future quality of life of children age 12 and above that have the specified genetic coding.

KEY THEORETICAL CONCEPTS

This section sets the scene and lays the foundations for this middle childhood sibling study by exploring relevant key theoretical concepts of family, childhood, home as a childhood space and sibling relationships. This is important because, whilst these child siblings are the main focus of this study, they are not viewed in isolation as they are viewed with their family. The exploration of these concepts provides knowledge and understanding to inform and enable the positioning of the work in relation to the social, cultural, political, historical and contemporary discourse that

has been presented within the literature. Sociological debates and theories are examined to demonstrate the transitional changes in family life and how childhoods/children are situated within these transitions of social change. It also presents the influential and bonded nature of the sibling relationship. Exploring this sociological discourse provides an essential framework that can allow greater understanding and insight when caring for children, siblings and their families within healthcare. Therefore this chapter is provided prior to the literature review, which focuses on the impact of chronic illness on the sibling.

1.6 WHAT IS FAMILY?

It is suggested that the term family can be perceived in different ways because it cannot be reduced to a singular definition (Thompson 2012, Cheal 2002). The concept of family itself is complex with theorists debating structural and functional perspectives (e.g. Malinowski 1930, Bell and Vogel 1960, Murdock 1960, Bales and Parsons 2014) and whilst the family can be considered as a nurturing environment where socialisation occurs, it is continually influenced by ongoing intergenerational change in relation to life events, the social world and perceptions of ones experiences (Cheal 2002, Hollway and Jefferson 2000). Hughes and Ferguson (2004) suggest that there is now a move away from the traditional view of family due to the increasing diversity of relationships and changed view of normal. They debate that moving away from the traditionalist stance does not mean that there is a breakdown in family life, but that it accounts for a new ordering of lives within the family.

Such new ordering can be related to the view that families are not homogenous and their heterogeneity needs to be recognised because the family can present in many forms (Cheal 2002, Hughes and Ferguson 2004). This can include having parents that are married, divorced, single, old, young or of the same sex. It may also include children with the same birth parents, which Parkin and Stone (2004) would refer to as a kinship and based on biological parameters. Alternatively it may include those

who are fostered, adopted or are part of a stepfamily. Parkin and Stone (2004) would suggest the latter creates an altered view of kinship that occurs when families substitute their biological relationships due to societal change. Children are essential members of the family but the concept of the child, children and childhood have been the subject of much debate historically and through to the present day by many eminent theorists (Rousseau 1762, Aries 1962, Aries 1973, Walther 1979, Katz and McClellan 1997, Gittens 1998, Prout 2005, James and Prout 2015). The exploration of which is discussed below.

1.7 DEFINITIONS OF CHILDHOOD AND DIFFERENTIATING BETWEEN THE TERMS CHILDHOOD AND THE CHILD

1.7.1 DEFINING CHILDHOOD

Several definitions of childhood are proposed within the literature with Aries (1960; 1986 p125) suggesting, "Childhood did not exist", and Jenks (1996) and James, Jenks and Prout (2007 p207) referring to the concept as a stage of becoming. Alternatively Ribbens McCarthy and Edwards (2011 p26) refer to idea of childhood as

"The state or time of being a child, as a phase of life that is understood both separate from and in preparation for being an adult".

On examining these definitions it would appear that historically there have been areas of uncertainty surrounding childhood as a concept, and initially some limited exploration in this area, which would link with the seminal work of Aries (1962; 1973) that will be discussed later in the chapter. Also in relation to using the term becoming (Jenks 1996; James, Jenks and Prout 2007) would suggest that this portrays children as being on a developmental journey over a period of time with the end point being adulthood. It could be perceived that childhood is a period of marginalisation and acquiescence, with the adult having superiority in focusing on their own significant needs and fears (Walther 1979). However

Ribbens McCarthy and Edwards (2011) definition is extended to recognise the separateness of childhood versus adulthood.

What the above definitions do not provide are concrete answers in relation to what childhood is, but all promote the need for further exploration. This helps to gain greater depth of meaning surrounding the concept rather than trying to reduce it to a single definition. Also Gittins (1998 p21) would suggest that it is essential to distinguish between the terms childhood and the child/children to ensure a clearer understanding, which will be alluded to before further progression into this text. This will help to avoid what Rousseau (1762) would refer to as developing a falsehood about an idea and moving into a misplaced direction where one becomes lost. However, first the seminal work of Aries will be addressed.

1.7.2 THEORETICAL CONSIDERATIONS

A predominant theorist who is often referred to in the literature when exploring the concepts of children and childhood is that of Phillippe Aries (1962; 1973). He has been mentioned earlier in this text and also in the work of Heywood (2004), Hwang, Lamb and Sigel (1996), Prout (2005), Scourfield et al. (2006), James and Prout (2015). With all of these works, it is alluded to that if one is going to conduct research with children, then seminal work of Aries (1962) should be acknowledged.

1.7.3 THE SEMINAL WORK OF ARIES

Aries (1962) suggests that the concept of childhood was not present in medieval times because childhood was non-existent. This is not to mean that there were no children, but that they lacked a status in their own right so the concept of childhood was not required (Aries 1962; 1973). The adult/child distinction was not yet formulated and Aries (1962; 1973) discussed that once the child no longer required maternal protection and nurturing from their mother or nanny to be able to survive, this early attentiveness was perceived as unnecessary. It was at this particular stage that they were then viewed as little adults. At the ages of seven and eight they could then be expected to take on a status of independence for

example; in carrying out chores, helping their parents, becoming servants or taking on a role as an apprentice. It was not recognised as much a time of innocence but a time of indifference and disdain (Aries 1962, Aries 1973, Gittins 1998, Heywood 2004). Martindale (1994) associates this portrayal of apathy and disparagement in this era to the high infant mortality rate, suggesting it was the parents' way of protecting themselves, against the loss, or potential loss of their child.

The characterisation of medieval childhood according to Berkvam (1983) was its unstructured nature and lack of order or specification. This can be recognized in the discussion of a monk in the ninth century named Hildemar who applied the term *infans* to represent an age range from 3 to 15 years (Schultz in Heywood 2004). There is no recognition of the stages of growth and development and the distinctive phase that is now recognised in latter years as the transitional period of the adolescent (Bill and Hodges 2007). Aries (1973) concurs that the differentiation between the child and the adolescent was not apparent until the 18th Century and that prior to then they were considered one and the same. This acknowledged change demonstrates a shift in the recognition of the concept of the child and the period of childhood itself. However Aries (1973) discussed that this alteration in the changing view of children began in the fifteenth century and carried on through to the seventeenth century. Hence he suggests that it was this specific era that enabled the progression and understanding of concept of childhood that exists in modern times.

His rationale here was that it was due to the family/child dynamic becoming more valued from an emotional perspective within society. Also the realisation that children would benefit from the experience of an institution where they could be controlled instructed and guided through their stages of immaturity. This institutional place was called a school and it was suggested that this is where children belonged (Aries 1973). Cunningham (1991 p7) supports the work of Aries (1973) with what is

referred to as 'irreversible change in the representations of childhood', as there was a transition towards global recognition for the rights of the child. Earlier, Rousseau (1762) was supportive of this gaining of rights as he encouraged a free spirited view, suggesting the endorsement of a life journey for children without prohibition and allowing them greater freedom. Whilst the work of Aries (1962) is a popular discussion in many texts (Heywood 2004, James, Jenks and Prout 2007, James and Prout 2015) it is also important to note that his ideas have been heavily criticised with some theorists disagreeing with his views (Archard 1993/2015, Nelson 1994, Martindale 1994).

1.7.4 CHALLENGING THE VIEWS OF ARIES

Archard (1993 p22) discards the idea that childhood does not exist by merely suggesting the idea of "presentism," where children are treated differently in a particular period of time because each was representative of that era. Therefore Archard (1993) concludes that versions of childhood do exist through time, but differ in their epitome and cannot be purely a symbol of modern times. Nelson (1994) concurs in suggesting that Aries (1962) did not take into account the alterations that took place over the centuries and makes the point that there was a misjudgment in his theory in respect of the lack of representation of the love that parents felt for their children in medieval times.

Perhaps such misrepresentation could be due to the historical portrayal of childhood imagery. Hwang, Lamb and Sigil (1996) discuss the varied images of childhood through the ages and how this has been influential in the development of education, policy, parenting patterns as well as aeration of children's rights.

Hwang, Lamb and Sigil (1996) argued that images have not always portrayed a realistic view of childhood and that some images merely depict the child as a miniature adult by the way in which they stand within the picture, almost mimicking the stance of the adult. Higonnet (1998) extends this view in suggesting that former artistic images focus on the

adult/societal story rather than capturing the true picture of childhood. This means that such images depict children in an indeterminate state, with the obliteration of sexual characteristic and social standing. These inaccurate portrayals have led to misinterpretation of childhood through the ages, as well as failure of developments in policy and education (Hwang et al.1996). A falsehood will remain if more accurate cultural aspect of child worlds is not presented. Romantic imagery of childhood implies a care free, innocent time, which is an idealization, which provides a false representation (Holland 1992, Higonnet 1998). Prout (2005) suggests a move away from this romantic idealism to represent childhood as more authentic. Such authenticity may include children who experience ambivalence, suffering and vulnerability. By facing such realities, important elements relating to childhood may be better understood and addressed.

1.7.5 DEFINING THE CHILD

Having explored the views and challenges of Aries, it is important to also acknowledge the work of Gittins (1998) who suggests that it is important to differentiate between the terms childhood and the child/children to ensure a clearer understanding, this will be alluded to before further progression into this text. This will help avoid what Rousseau (1762) would refer to as developing a falsehood about an idea and moving into a misplaced direction where one becomes lost.

Gittins (1998 p6) and Heywood (2004) discuss the child in terms of 'other' i.e. not an adult, but an embodied being, who is experiencing an ongoing change in their chronological growth and development. The child is one who is dependent, powerless and reliant on the cultural assumptions and expectations of the adult. Their lack of autonomy can place them in a position of vulnerability, whereby there have been historical instances of them being ridiculed, ignored or held in contempt by the adult (Walther 1979). Unfortunately this can still be the case in the present day, which has led to more serious consequences for the child (e.g. Child protection reports such as Climbe / baby P cases (Laming 2003, Laming 2009)). Lee (2001) also acknowledges the silenced child, whose voice is not heard.

Rousseau (1762) suggests that the child is born innocent but is corrupted in the adult world. Equally Aries (1973) depicts the child as being available for adults' amusement with reference to Goussault ([1693] in Aries 1973 p129; 360) who suggests that by winning a child over with sweetness that they become easy prey to manipulate and doing what one wants with them. It is suggested by Goussalt (1693) that by being nice to the child, the adult can aim to build a trusting bond with them, but this is not always for the best interest of the child. Aries (1973 p6) also refers to a term called "coddling" that occurred in families with small children (Historically usually of the higher social classes). "Coddling" later became an occurrence of those placed in the group of lower social class. An important point that is raised by Aries (1973) is that the fondness and love one might have for a child or children must not be confused with the issue of childhood as a concept.

What has become evident in exploring several definitions/theories of childhood, and that of the child is, that they have separate distinctions but also some commonalities. Whilst Gittins (1998) suggest that discussions surrounding childhood focus on a period of time rather than an individual, she also adds that childhood and child/ren define one another. However: Prout (2000; 2005) and Prout and James (2015) suggests that childhood is affected by societal instability which has led to a blurring of the boundary between adults and children where the peculiarity between them is no longer so clear.

One might question how the child/adult boundary is perceived within the literature and why and how this blurring exists? This leads into the next section where theories surrounding childhood will be elaborated and the historical progression towards contemporary practice captured. Gaining an understanding in this area is essential, as it provides the underlying foundation to my own work.

1.7.6 DEVELOPMENTAL THEORIES OF CHILDHOOD

It is not only romantic imagery that portrays a lineal view of childhood. The developmental psychologists, Jean Piaget (1952) and Sigmund Freud (1962) both lack a cultural observation in their early exploration of child development. Piaget (1952) proposed the theory of the cognitive development of the child, with the focus on the child as an embodied being that will grow and develop. He describes the chronological stages of development that a child will pass through to demonstrate a level of intellect as well as biological adaptation at each stage ranging from; sensori motor in infancy to formal operational in adolescence and adulthood. According to Piaget (1952), it is not until the latter stages with the move towards adulthood that one can problem solve and master abstract thinking.

Freud (1962) focuses on psychosexual development of an individual with the association between personality and sexual fixation in the transformative process of becoming an adult. He proposed three fundamental principles namely the id, ego and superego whereby the id signifies the early development of the child in relation to pleasure seeking and the pleasure principle. The ego is a stage where the child can interact and experience others through the senses and the id becomes less of a focus and is more contained. Then finally the superego resonates with the presentation of self into the realms of the adult world where childlike behaviours are no longer acceptable (Mitchell and Ziegler 2013, James, Jenks and Prout 2007).

Whilst Piaget (1952) and Freud (1962) are renowned for their theories, they have also come under criticism from others (Donaldson 1978, Vygotsky 1978), one reason being that they place adulthood as an endpoint, something one works towards which links with the earlier discussion of becoming. This idiosyncratic notion cannot be viewed in isolation and Bradley (1989) suggests that it is time to move away from a

lineal view where the end stage of development is adulthood and childhood is left behind

Mitchell and Ziegler (2013) discuss Piaget's (1952) lack of insight into how the social experience of the child impact their developmental journey along with their early capability of understanding their own mind as well as the mind of others. For example a child with special needs or chronic illness may not pass through these stages so systematically. Piaget's theory has also been linked to constructivism, whereby knowledge is constructed as one develops (Mitchell and Ziegler 2013). Vygotsky (1978) promotes an expanded view referred to as social constructivism, suggesting that the culture that a child belongs to will influence their language development, intellect and construction of knowledge. Recognising the influence of the social context is a fundamental aspect of the Vygotsky theory (1978).

1.7.7 THE 'DISAPPEARANCE' OF CHILDHOOD

Changes in the social and cultural context of children's worlds, has led the theorists below to provide a differing perspective.

Elkind (1981), Postman (1983), Kincheloe and Steinberg (1997) and Winn (1983) are all eminent authors on the disappearance of childhood. They challenged newly emerging constructs of childhood by questioning their ontological status. They interpret late twentieth century change in childhood as a sign that childhood as a social institution is in the process of disappearing rather than changing. Appalled by the breakdown of the boundary between adulthood and childhood, which they regard as historically progressive and necessary, they blame technological innovations such as the television and the Internet. The above theorists argue that society is leading to the disappearance of childhood by making a wider range of information available to children.

The claim that childhood is disappearing finds resonance in all kinds of public debates and concerns particularly as many children are under increasing pressure to succeed in the school system that is subjecting

them to earlier testing systems. Prout (2005 p14) discussed the work of the eminent authors above and concludes that; “The secret garden of childhood” remains a significant topic for discussion. Similar reference has been made to the garden of childhood by Beck (2002; 2003) in her PhD thesis as she recognised the garden of childhood to represent a place of play as well as a cultural symbol that reflects societal transitions and concerns. She relates the Garden of Eden to the disappearance of childhood and makes reference to the book ‘Toms midnight garden’ in which she perceived the garden to be placed as a place of escape from the contemporary world in which the child lives.

Despite the concerns of Elkind (1981), Postman (1983), Steinberg and Kincheloe (1997) and Winn (1984) with regard to technological advances and the pressure that they highlight is placed on children, Katz (1997) in Prout (2005) supports technological change. Katz (1997) in Prout (2005) suggests that these previously discussed transitions provide children with a greater political standing and interconnectedness because they have been freed from socially imposed limitations and intergenerational expectations where they were not consulted with regards to their best interests. Therefore, Prout (2005) advocates for a more contemporary view of childhood to be considered within this exploration of the theory of childhood. This shift towards a contemporary view is important as it has relevance with the nature of my own study.

1.7.8 CHILDHOOD: A CONTEMPORARY FOCUS.

Prout (2005) suggests a repositioning of childhood, away from traditionalist perceptions of the past, towards a focus on new constructs of childhood where children are viewed as active participants in society. This is referred to as the social constructionist turn. He suggests that it is only by leaving behind conventionality that the realities of childhood and the experience of children will emerge and be highlighted. He suggests the need to eliminate the gap between the idealised portrayal of childhood and the discordant realities that children face, if we are to recognise their needs within our now fast-paced and transitionally volatile times. Prout

(2005) suggests this gap between the ideology and reality is a global issue. The work of Prout (2005) and Prout and James (1997) has been updated in Prout and James (2015) where such childhood issues remain under discussion as they are reiterated in their discourse of ‘provenance, promise and problems’ (p7). Prout and James (2015) re state the position of what they suggest remains a transpiring paradigm for the new sociology of childhood and includes six key attributes. Due to their relevance and important nature for this study, they are outlined in their entirety in the table below:

Table 2.

	Key attributes for the new sociology of childhood in Prout and James (2015) page 7.
1	Childhood is understood as a social construction. As such it provides an interpretive frame for contextualising the early years of human life. Childhood as distinct from biological immaturity is neither a natural or universal feature of human groups but appears as a specific structural and cultural component of many societies.
2	Childhood is a variable of social analysis. It can never be entirely divorced from other variables such as class, gender, or ethnicity. Comparative and cross- cultural analysis reveals a variety of childhoods rather than a single and universal phenomenon.
3	Children’s social relationships and cultures are worthy of study in their own right, independent of the perspectives and concerns of adults.
4	Children are and must be seen as active in the construction and determination of their own social lives, the lives of those around them and of the societies in which they live. Children are not just passive subjects of social structures and processes.
5	Ethnography is a particularly useful methodology for the study of childhood. It allows a more direct voice and participation in the production of sociological data than is usually possible than is

	usually possible through experimental or survey styles of research
6	Childhood is a phenomenon in relation to which the double hermeneutic of the social sciences is present (See Giddens 1976). That is to say, to proclaim a new paradigm of childhood sociology is also to engage in and respond to the process of reconstructing childhood in society.

The parameters above have been suggested to provide insight into the contemporary paradigm of childhood, as well as provide a guide for consideration and for further study (Prout and James 2015). What they are not meant to be, are structured rules that one should not deviate from, as there can be flexibility within an approach to studying/researching children and childhoods.

In recognising the value of the differing historical and contemporary perspectives and transitions relating to the concept of childhood that have been discussed, this study draws on the notion of the social constructionist turn and views childhood through the new social studies of childhood lens with particular emphasis on the being child. According to James, Jenks and Prout (1998 p207) the 'being' child is a person that is recognised as having their own status as a social actor. They are able to perform a particular course of action because they have their own set of needs, rights and differences and so they can be understood in their own right. Wartofsky (1981:199 in James, Jenks and Prout 1998) would suggest that the child, who is an active agent in their own right, is able to initiate such actions by their own choice just like any adult would do.

Recognising the child as 'being' allows a shift away from the blurred boundaries that can exist between adults and children as Prout (2005) suggests that they are no longer clear. Prout (1997) suggests that children should not be stereotyped or misunderstood but that they should be listened to and recognised for their own personhood. Wyness (2012 p32) refers to this as 'bringing the child into view' whereby they can have

their own voice as they have the right to be heard. This is important if children are to become more visible (Wyness 2012).

The theories of childhood discussed above have provided an insight into the historical debate/discourse relating to the concept, but they do not provide concrete answers in relation to what childhood actually is because the debate surrounding the concept needs to remain open according to Prout (2007). He suggests a refrain from reaching definitive conclusions because there is a need to recognise the diverse nature of childhood locally, globally and historically within and between different societies, cultures and social time scapes. Therefore it would appear that childhood is a complex, constantly transitioning concept as opposed to one that is static, but what is clear from a contemporary perspective is that childhood studies are still under-represented and that the voice of the child needs to be heard in order to capture periods of childhood to enable an understanding of the temporality of their lived moments in the present day.

Pufall and Unsworth (2004) suggest greater interdisciplinary engagement between practitioners and research theorists in the childhood field to enable the sharing of knowledge as well as provide an understanding or insight into its application in practice with regard to children's experiences. They currently view practitioners and researchers as working in their separate silo's with an absence of interaction, but suggest if an interactive model was applied in relation to research and practice then greater understanding of childhood would exist and it would also be for the greater good of the child as well as their family. This is pertinent to this research because it crosses interdisciplinary boundaries with sociological and healthcare perspectives being considered.

1.7.9 THE CHILDHOOD SPACE OF HOME

The spaces that children encounter are important aspects and influences within their worlds as they add to the context of the interactive situations that they find themselves in, so it is important that childhood space is also recognised. A particular space of recognition is that of the children's

family home because it is normally a safe and protected place for the child (Lee 2001). It is in the home environment where the child has space to grow and develop with the guidance of their parents/key carers'. Having the confinements of the walls of this space allows privacy from the outside environment, which is a more public world (Lee 2001). However with reference to the disappearance of childhood that was mentioned earlier, Postman (1983) suggests that since the introduction of television in the home, the childhood space is not as private as it was and technology is seen to have an influence on the child's private world.

Buckingham (2000) would add to this discussion that the intrusion of technology (to include television, cable as well as interactive computer games and the internet) has made the childhood home space more complex as opposed to causing an innocence of childhood to disappear. Buckingham (2000) also suggests that children still have privacy in their home but they also have choice in terms of their interactions and influences, which he believes is their right. Hadfield et al. (2005) recognise the home space as a place where childhood siblings can act out/externalise their feelings towards each other when they are together or apart. Edwards et al. (2005) also identify the importance of the use of differing rooms and spaces within the family home. Hence the family home is viewed as an important interactive space and will be considered in this study.

1.8 THE SIBLING RELATIONSHIP

Many pertinent studies have explored the relationships of siblings; Dunn and Kendrick (1982), Brody (1998), Edwards (2006), Cicirelli (1995), Goldenthal (2000), Hadfield et al. (2005), Hadfield et al. (2006), Stark (2006), Sanders (2004), Rowe (2007), Dunn (2008), Doherty and Coleridge (2010), Lucey (2010). A noted seminal piece of work is that of Bank and Kahn (1982) who explored the sibling bond in great depth.

1.8.1 SIBLINGS BONDED

Bank and Kahn (1982) and Rowe (2007) suggest that a sibling can be an important and influential person in one's life from the moment they first meet, and right throughout the sibling's life span. They state that being a sibling is a lifetime journey of sharing memories and experiences, which can be good or bad, pleasurable or painful, conflicting or comforting. It is within this relational trajectory that Bank and Kahn (1982 Pxvii), Edwards et al. (2006) and McGuire et al. (2000) suggest that siblings are "co-voyagers" that are co-constructed through their family interactions, influences and encouragements as well as conflicts. Bank and Kahn (1982) suggest that the childhood sibling relationship is not optional, but can become so, when siblings reach adulthood where it is then that they have a choice of whether to spend time together. Regardless of a sibling's relationship being good, bad, indifferent or ambivalent, the sibling bond remains because siblings formulate and influence each other's past, present and future.

1.8.2 SIBLING CONNECTION

Within the childhood sibling "co-voyage" discussed by Bank and Kahn (1982 Pxvii) it is important for siblings to feel a sense of belonging in being part of a family and in having a connection with their sibling. It is through these early connections, that siblings formulate their real, inner most private selves (James 1890). However contradictory to this want for togetherness, the sibling can engage in an inner struggle in also wishing to acquire a need to be an independent self where their individuality is recognised (Edwards et al. 2006). By maintaining togetherness along with striving for individuality, Edwards et al. (2006 p37; 38) found that siblings identify themselves through the comparative realm of "being the same" or "being different".

Through sameness and difference, Edwards et al. (2006 p37; 38) refer to an intertwined notion where siblings are able to identify and express their unique self in terms of their physical differences, preferences and personalities. This can frame their sense of identity, which is

interconnected with their emotional composite of dependence versus independence. The comparisons of these notions are not solely observations of the sibling because they also arise from comments made by other family members and are also influenced by an external social world to which they belong. Other influences of the sibling identity of same and difference are “gender, race, class, culture and history” (Edwards et al. 2006 p38).

This contradiction of wanting to feel a connection with their sibling but also wanting their independence can lead siblings to begin to set boundaries in their relationships with their brothers/sisters. They can make boundary distinctions of their possessions in terms of what they own themselves and what belongs to another, as they differentiate between the concepts of what is mine and what is yours (Bak and Ross 1996, Ruble et al. 1980, McGuire et al. 2000). Boundary setting is not exclusive to protection of possessions but also to that of protecting one’s space within the family home. It is here where siblings may display notices such as the example provided by Stark (2007 p11) that states “No Trespassing”. Such a sign was exhibited to make it clear what space is there’s, giving a definitive message to their brothers and sisters. Boundary setting is part of sibling’s social development in their journey toward independence and it links into the notion of difference stipulated by Edwards et al. (2006 p6). This aspect of social development and formation of one’s temperament can influence the harmonious equilibrium of family life (Brody 1998 p2).

This harmonious synchronisation can also be influenced by the positive and negative feelings that siblings can have for one another that are exhibited in their daily interactions (Edwards et al. 2006, Brody 1998 p2). Child siblings can spend much of their time in each others company, more so than with their parent and as a consequence they become aware of each others idiosyncrasies which provide them with knowledge of what will please their sibling and what will not (Klett-Davies 2008). This privileged

knowledge of other can be used when the sibling chooses to be a source of comfort or conflict to their brother or sister.

Such comfort can be provided in times of distress, if a sibling can see that their brother or sister is upset and requires a supportive companion to ease their woes and listen to their concerns (Dunn in Klett-Davies 2008). Edwards et al. (2006) presented sibling narratives that demonstrated the protectiveness, empathic warmth and caring traits that can occur when siblings are looking out for one another. There is a suggestion that siblings can be dependent upon each other for companionship and play, so as to avoid being alone and isolated.

However, Edwards et al. (2006 p47) also recognised in the same sibling narratives, the source of conflict that was projected when siblings talk of arguments, bickering, moments of antagonism and indifference. An example given was when a sibling spoke of how he perceived his brother to manipulate his parents in order to 'get his own way', as well as feelings of when his brother invaded his space. This led to conflict between two brothers with one of them at times wishing to remove his sibling from places and moments in his life. Dunn in Klett-Davies (2008) recognised such conflicts as resulting from siblings knowing each other so well, leading to them knowing what would annoy one another as well as knowing what sibling reaction would prevail. Munn and Dunn (1989) suggest that differing temperaments of siblings may also be influential in their conflict where their temperaments were seen to be dissimilar. However, Stoneman and Brody (1993) suggests that if a sibling has more positive temperament attributes, this can help them to counteract the potential unfavourable impact of living with a sibling with a negative personality attribute. Bedford et al. (2000) suggest that sibling conflict can result in positive outcomes for siblings as it can help them to develop social competence in terms of dealing with different situations, as well as help in the formation of their identity and development of self. Edwards et al. (2006) suggest that sibling's experiences of positive, negative and

ambivalent feelings towards each other influence their emotional development as well as the quality of their relationship.

1.8.3 PARENTAL INFLUENCE ON THE SIBLING RELATIONSHIP

It is not solely sibling interactions themselves that are seen as responsible for the quality of sibling relationships, but that of differential treatment and quality of attention provided by their parents (Coles 2003, Mitchell 2003, Brody 1998, Brody et al.1992, Dunbar 1999, Howe et al. 2001, Sanders 2004). According to Sanders (2004) it is parents who are role models for the social interactive processes within the family. Children are recipients of their parenting styles and for some siblings an absence or limited amount of emotional and physical attention can lead to a co-dependence of siblings on one another and a stronger sibling bond, as they compensate for this lack in quality parenting by relying on each other more (Bank and Kahn 1982).

When parental attention is available, siblings are quick to notice differential treatment in terms of one being treated more positively than the other. This may include where one sibling is given more time and attention or given a specified role that may be considered a greater accolade than another given role. It may also include differing levels of discipline or exhibition of praise and the appearance of favouring one over the other (Sanders 2004, McHale et al. 1995, Volling and Elins1998). Transitions in approaches to parenting at given times can also be an influence in the sibling relationship because parenting patterns are not always consistent and their skills may change over time due to their prior experience. Siblings may be quick to notice their differing skills and decisions and view this as unfair treatment (Sanders 2004).

Where both siblings are treated fairly and with positive demise, this can lead to positive relationships between siblings. However, if this is not the case and one sibling feels that they are being neglected of attention and treated less favourably, then their can be an upsurge of negative feelings which include jealousy, anger, fear and rivalry (Brody 1998). This can

impact on a child's self esteem as well as the quality of the sibling relationship and can generate a competitive as well as the aforementioned sibling conflict, as siblings compete for parental attention. When siblings want favourable attention they may engage in competing to be seen as good.

1.8.4 BEING A GOOD SIBLING

Rowe (2007) discusses an aspect of the sibling relationship in terms of competing to be a good sibling when being cared for by a parent. Good meaning that one must act in a favourable way so as to meet the beliefs and values that are defined as being good by that person who is looking after them and who is also passing judgement on their behaviour. If the sibling is good they will be praised and looked after as opposed to be scorned or held to account if something goes wrong. Rowe (2007) expresses how siblings learn about being good from each other as they compare themselves as they strive to be seen as being better than the other. Sometimes to demonstrate being nicer than the other, siblings can place blame on each other for wrong doings, faults and misdemeanors. Within this competition siblings interact and learn behaviours that enable them to take a responsibility of one self and live by a code that is seen as acceptable by the caring parent. Rowe (2007) suggests that by being good a sibling one enters into a contractual agreement where the reward will be to be taken care of by their parent.

Entering into this contract also means a divide for the child sibling, because they can split themselves into two personas where they are taking responsibility to look after themselves as well as effectively being their own inner parent. Along with this they are maintaining being a child, one who wants and needs to be looked after. An important point to note is that siblings can also compete to be bad, if that is seen as gaining them a gratified sense of attention. This competition whether for good or bad along with the self divide is stated to move with the child through to adulthood. Parental response to the competitive behaviours of siblings can have an influence on the sibling's growth, development and their

interactions with one another and can equate for sibling differences, despite being raised in the same family (Stocker and Dunn 1994). What can also be influential is the sibling developmental age (Sanders 2004). For the purpose and relevance of this study the sibling in middle childhood is focused upon for discussion below.

1.8.5 THE SIBLING IN MIDDLE CHILDHOOD

In Western society middle childhood is referred to as the school age child but from a developmental perspective Piaget (1954) would suggest the age of 7 years to 11 years as middle childhood. Piaget (1954) put forward the cognitive development stage of concrete operational, a stage where the child is able to demonstrate logical thinking and understanding of people, events and situations in their environment (Adams 2012). However the age range for middle childhood has been open to interpretation, with suggestions of the age of 5 or 6 being the starting point of this phase of development and ending between 10 or 12 (Broderick and Blewitt 2006).

Whilst these differing interpretations exist it is important to acknowledge that middle childhood is a particularly important stage of life for the sibling, because it is where there is evolvment of the child's social world and greater focus on play, activities and educational pursuits. Equally it is a time where alteration in the child's relationship with the family and surrounding environment is encountered. Children are being exposed to new experiences in their life, peer acceptance is important to the child at this stage, but the family still has a key influence in the child's development (Charlesworth, Wood and Viggiani 2011). Additionally Selman (1976) suggests it is this stage where the child is able to self reflect and view their behaviour, emotions and thoughts from the perspective of others. Edwards et al. (2006) draw on the importance of studying siblings in middle childhood in their own childhood study.

1.9 CONCLUSION

An overview of the disease cystic fibrosis and its treatments has been presented to provide the reader with an insight into the condition, so as to enable greater understanding of the contextual issues discussed in this study.

The exploration of the theoretical foundations within this chapter has also highlighted the complexity surrounding the concepts of family and childhood as they are ever changing in a transient world, so cannot be positioned as static. Children and their families are continually altering and adapting in their worlds due to social, developmental and technological influences that are placed upon them. In a new ordering of family unit, children their siblings, parents and or carers all remain connected and bonded in their parallel lives as they are influential to each other and can evoke alterations in their presentation of behaviour as a consequence of their daily interactions (positive or negative) and their social spaces in which they live. In relation to this study this reiterates the importance of studying the sibling in the context of their family life in their home environment. What is also highlighted in this chapter is the need for children to be viewed as agents/ social actors in there own right, so that they can be brought forward and have their own voice heard. This notion provided a key theoretical underpinning for this study in recognising the child as being.

What the literature does not address here is how the added complexity of having a child with a chronic illness within the family adds to the influence of an already complex transient family world in terms of child/sibling interaction within their family environment. The next chapter will draw on further literature but from a healthcare perspective to add further insight into the positioning of the work and the need for this study.

1.10 OVERVIEW OF THE THESIS

This section provides a synopsis of each chapter within this thesis:

Chapter 1: Laying the foundations: Key theoretical concepts

Chapter one presents an autobiographical narrative and a positional statement of the researcher prior to discussing the theoretical foundations for this study. It provides background information in relation to the disease of cystic fibrosis along with the key concepts of family, childhood, and home as a childhood space as well as theoretical insight into sibling relationships.

Chapter 2: Literature review

Chapter three presents healthcare foundations for this work as it identifies the literature that was accessed and retrieved using a stated search strategy. Practical, political and theoretical insights are discussed and gaps are outlined to inform the research study. The impact on the sibling of living with a brother/sister with chronic illness is also presented. The discussion in this section also highlights the political and historical drive towards the provision of family centred care in children's nursing practice.

Chapter 3: Methodology and methods

Chapter four takes the reader behind the scenes to the preparation that occurred in order to take forward the research study to enable the outcome of a dramaturgical production. The multiple roles of the researcher are discussed throughout the chapter, however the chapter is divided into three sections.

Section one provides an insight into the epistemological, ontological and methodological position of the study. Hence there is a discussion surrounding dramaturgy as well as outlining the view of children as social actors/ engaging in interaction.

Section two outlines the reason for choosing a qualitative study and the rationale for the choice of methodology as narrative inquiry. This section also discussed the interdisciplinary methods that were used to engage children to participate within this study and it presents a discussion of the bricolage. The bricolage presents methods of narrative interview, visual creations, observations and researcher reflexivity.

Section three discusses the recruitment strategy, as well as the putting into practice the methods used to collect the required data. The formats of the field visits are discussed along with challenges faced. The data analysis strategy is also outlined as well as the ethical considerations for the study.

A three act play called “Segments of the sibling mosaic”

Following chapter four, the play ‘segments of the sibling mosaic’ begins and is presented in three chapters in three key Acts. The play draws on the work of Goffman (1959) and focuses on the dramaturgical ‘lens’ in presenting and analysing each scene and act where front stage, back stage and centre stage roles, performance/presentation and position are discussed.

Chapter 4: The Prologue

The prologue presents a reflection of two significant scenes that emerged for the researcher when conducting this work. It represents a past meeting the present moment. The prologue is presented for transparency.

Chapter 5: The exposition: Introducing the protagonists, setting the scene and the stage settings.

This chapter introduces each of the sibling participants as actors/protagonists in this study and presents their key home stage sets. It also presents the protagonist along with their sibling/s with cystic fibrosis and family group in stating their situational context. Children with cystic fibrosis are identified as being antagonists for the purpose of this work.

Chapter 6: Act 1. The decentralised sibling

Several scenes are selected within this first Act to incorporate the analysed themes that relate to sibling positioning within their family. Key scenes are presented within the stated themes below:

1. Siblings in “the wings”.
2. Siblings “left of centre”.
3. Siblings in “off stage place sets”.

These scenes highlight the positional status of the sibling within the family; this is demonstrated through several interactions that are presented. It also highlights the influence of positioning on sibling use of space in the family home. The chapter includes dramaturge fantasia as a means of reflective metaphorical expression.

Chapter 7: Act 2. The importance of being good

This chapter focuses on the front stage performances of siblings where they bring elements of the self to the stage and contribute key scenes that are representative of the themes below:

1. Presenting “perfect selves”
2. Presenting “perfect pictures”
3. “Other ways of being good”

The “importance of being good” explores the multiple ways that the protagonists idealise the self and the family through a variety of creative media, as well as through their performances and narratives, as they strive to be seen as good and avoid an exposure of their back stage presence. The chapter highlights the protagonist’s ideology and the concealment/avoidance of presenting an authentic self.

The chapter also includes dramaturge fantasia as a means of reflective metaphorical expression.

Chapter 8: Act 3. The contradiction: Journeying alongside cystic fibrosis

This chapter returns to the back stage worlds of the protagonists as they journey alongside their brother and or sister in the cystic fibrosis trajectory. It reveals some powerful moving accounts, revelations and highlights the emotional labour that the protagonists encounter in particular situations and interactions that they are faced with in their cultural milieu. The chapter presents sensitive sibling presentations of their private selves as they move away from a front stage façade that is a contradiction of the earlier presented idealised self. Siblings also speak of their imagined futures as they discuss and present their visions that for some relate to aspects of caring and a move towards independence. Four key scenes are presented, with one scene being lengthy due to the nature of the dialogue that is presented.

The scenes make up the themes stated below;

1. “Authentic moments”
2. “Then and now”.
3. “Future selves”.

The chapter also includes dramaturge fantasia as a means of reflective metaphorical expression.

Chapter 9: Discussion and Conclusion

Chapter ten brings together the segments of the sibling mosaic to formulate an overall sibling portrait that is discussed in relation to the dramatic framework. It highlights key issues for practice, policy and education. Recommendations are also outlined and study’s strengths and limitations are highlighted.

“Why sometimes I’ve believed as many as six impossible things
before breakfast”

“Curiouser and curiouser”

Alice in Wonderland

Lewis Carroll

CHAPTER TWO- LITERATURE REVIEW

2. INTRODUCTION

This chapter presents the literature that was reviewed prior to and during conducting this research study. An outline of the search strategy is presented in appendix 1 along with the stages of the search outlined. There is a discussion relating to the impact of cystic fibrosis on the family as well as the impact of chronic disease on the sibling. The concept of family centred care in children's nursing is discussed with an emphasis on historical, political and practical issues. This review adds to the foundations that have been established in the previous chapter to provide further insight into existing knowledge as well as to identify gaps within the literature in relation to the chosen topic areas.

Due to the nature of this study with regards to researching siblings within the context of their family, the literature review incorporated an exploration of the impact of cystic fibrosis on the family as well as focusing on the siblings with chronic illness. The impact on the family is presented later as well as acknowledging some historical studies, to add to the discussion in order to identify what was known and not known in conducting my research.

Further studies that have been explored in relation to the impact on the family when caring for a child with chronic illness mainly concentrate on the specific care requirements of the chronically ill child because their needs are viewed as paramount (Sartain et al. 2000, Spilkin and Ballantyne 2007, Valentine and Lowes 2007, McMenamy and Perrin 2008, Martinez and Ercikan 2009, Beacham and Deatrck 2015). Additionally there is emphasis on the attitudes, perspectives and needs of the parents particularly the mother due to the perception that they are the child's primary care giver (Melnyk 2001, Berge et al. 2006, Hughes 2007, Shields et al. 2004, Monaghan 2009, Shields et al. 2009). More recently there is a

greater recognition of the role of the father (Ahmann 2006, Cashin et al. 2008, Waite-Jones and Maddill 2008, Higham 2011). However a member of the family that has limited recognition when living with a chronically ill child is that of the sibling within the context of their family, as they do not take priority and their needs are largely unmet (Murray 2000, Operman and Alant 2003, Labay and Walco 2004, O'brien 2009). The wider focus of the interactive nature of the family also does not appear to be addressed as the mother and father is studied in isolation as opposed to being within their wider family context.

2.1 THE IMPACT OF CHRONIC ILLNESS ON THE SIBLING

The previous chapter identified the sibling as a significant member of the family who can provide a practical and social role that can influence growth within the family relationships. They can be a great source of support in times of crisis; equally they can also be a cause of conflict when they are finding it difficult to manage (Brody 1996, Sanders 2004). Having a chronically ill brother or sister can add a new dimension to their world due to many amendments and challenges that are encountered alongside the disease trajectory within their family lives (O'brien 2009, Knecht 2015) the impact of which will now be discussed.

The main focus of the review has been conducted to focus on siblings living in the context of chronic illness, which identifies the limited availability of literature available in relation to siblings living with a child with cystic fibrosis, however some historical studies are acknowledged here.

2.1.1 RECENT LITERATURE EXPLORING SIBLINGS LIVING IN THE CONTEXT OF CHRONIC ILLNESS

Recent literature reviews that were conducted by O'brien (2009) and Knecht (2015) to explore the impact/perspectives of chronic illness on siblings, demonstrate that there are a limited amount of contemporary studies available that focus specifically on the impact on siblings who are living with a brother or sister with the chronic disease of cystic fibrosis.

Reviews of the literature by Williams (1997) and a meta-analysis of the literature by Sharpe and Rossiter (2002) does acknowledge some studies (although a minimal number) of siblings living with children with cystic fibrosis amongst other studies of chronic illness. Other key studies focus on siblings of children with cancer (Vermaes et al. 2012, Murray 1999; 2000, Sloper 2000, Essen and Enskar 2003, Barrera et al. 2004, Packman et al. 2004, Labay and Walco 2004, Houtzager 2005, Wilkins and Woodgate 2005, Woodgate 2006, Hamama et al. 2008, Alderfer 2010). Further literature focuses on siblings of children with autism (Kaminsky and Dewey 2002, Hastings 2003, Pillowsky 2004, Weissman 2004, Ross and Cuskelly 2006, Mandleco and Webb 2015), siblings of children on the bone marrow transplant trajectory (Wilkins and Woodgate 2007) and siblings of children with diabetes (Hollidge 2001). A study by Mulroy (2008), explores siblings of children with the conditons of Retts disease and downes syndrome.

There was a predominant focus in the research studies above, of the use of quantitative methodology. Key methods included questionairres, structured interviews and specific measurement inventories. O'Brien (2009) and Knecht (2015) highlighted the above researcher's methodological approach in their own review of the literature. However, Woodgate (2006) used a qualitative design, which included interviews and observations of siblings when they visited the hospital as opposed to being in their home environment. The studies did not use a creative design or visual methods.

Each of these studies present a multitude of contradictory issues demonstrating that some siblings function well in some aspects of their lives but some siblings do not, when faced with living with a brother and/or sister in the context of the chronic illness trajectory. The studies present some of the identified effects, which, are categorized within the literature using the terminology of negative impact and positive impact on the siblings' wellbeing. However for the purpose of this review the key themes

will be more clearly identified.

2.1.2 SIBLING EMOTIONAL WELLBEING

The emotional response of siblings living with a brother or sister with a chronic illness was highlighted as a key theme within the literature. Sharp and Rossiter (2002) suggest that sibling emotional responses demonstrate the negative effect it has on them in having a brother or sister with a chronic illness particularly in relation to their psychological functioning. This was highlighted because siblings demonstrated internalised behaviours of depression and anxiety. Sharp and Rossiter (2002) suggest this internalisation of emotion is worse for a sibling, when their brother or sister has a chronic illness that impacts on their everyday functioning due to daily treatment regimens. They also add that parents report more negative responses of the non-chronically ill child's psychological wellbeing than the sibling themselves and they comment on the over protectiveness of the parent. They suggest that siblings may choose to not acknowledge their own negative feelings until they reach adult life.

The emotional response of the sibling is not just specific to their internalised feelings as mentioned above, but also demonstrated in their externalised emotions as discussed by Murray (2000). The study identified that siblings of children with cancer experienced a range of emotions/feelings, which included anger and guilt as a consequence of their brother or sisters illness. Siblings also expressed negative emotion in terms of not feeling good about themselves, which is categorised as having a poor concept of oneself. Murray (2000) attributes these negative emotions to the sibling perception of their parents being more distant with them because the focus is on their chronically ill brother/sister. This can lead to feelings of rejection, isolation and anxiety in relation to being separated from their parents. As a consequence they do not feel that their emotional needs are being met and Murray (2000) suggests that negative feelings are experienced because sibling needs are being overlooked. Other studies concur in recognising that siblings experience emotional deprivation, which can also cause sorrow and/or despair for the sibling

(Bellin and Kovacs 2006, Van Riper 2003, Knecht et al. 2015).

The emotional status of siblings was also highlighted by Hollidge (2001) in relation to the psychological adjustment of the sibling when living with a child with the chronic illness diabetes. The study concurs with the previously mentioned studies of Sharp and Rossiter (2002) and Murray (2000) as well as a diabetes study by Wilkins and Woodgate (2007) where child siblings demonstrated a range of emotions, which included anger and sadness and feelings of distress in response to their brother or sister's illness. Hollidge (2001) found that 'healthy' siblings reported increased levels of anxiety, worry and sensitivity in a set of standardized tests as well as in semi-structured interviews. They also demonstrated symptoms of depression but not on a clinical depression scale. Additionally siblings were found to exhibit emotions of jealousy and competitive behaviour, because their chronically ill sibling was gaining more attention than them. In congruence with Murray (2000) the sibling expression of guilt is identified because siblings do feel bad because their brother/sister has to have injections due to their diabetes and they do not. Experiencing such a range of emotions does impact on how the 'healthy' siblings feel about themselves. However, Hollidge (2001) reports that 'well' siblings do play down their feelings, leading to internalization of emotion. As a consequence Hollidge (2001) would concur with Murray (2000) in suggesting siblings of the chronic illness diabetes, are a vulnerable group of children whose needs go unnoticed.

Conversely such vulnerability was not identified in a study that was conducted with siblings of children with autism (Macks and Reeve 2007). Instead they found that siblings of children with autism demonstrate greater levels of positive emotional and psychosocial adjustment than siblings that have a non-disabled brother or sister. This is synonymous with earlier studies by Kaminsky and Dewey (2002) and Pillowsky et al. (2004) who also report that siblings of children with autism are well

adjusted psychosocially. According to Macks and Reeve (2007) siblings of children with autism scored themselves favourably in relation to their behaviour, school achievements, level of intelligence and levels of anxiety. They conclude that siblings of children with autism do have a positive view of self, however they suggest this positive view could be influenced by the difference they see between themselves and their autistic sibling.

Despite the positive emotional findings in the studies that focus on autism (Macks and Reeve 2007, Kaminsky and Dewey 2002, and Weissman et al. 2004), Alderfer (2010) conducted a systematic review of the psychosocial adjustment of siblings with cancer that concurs with the work of Murray (2000), Sloper (2000), Woodgate (2006) and Hamama (2008) and highlights that siblings of children with cancer experience post traumatic stress symptoms with emotional reactions of shock, worry and sadness.

2.1.3 CHANGES IN FAMILY LIFE FOR THE SIBLING

In addition to experiencing a range of emotions as discussed above, siblings living with a child with a chronic illness can also encounter changes in family life due to the demands of their brother or sisters condition. Woodgate (2006) examined what family life was like for 'healthy' siblings with a brother or sister with chronic illness and found that siblings reported a loss of family life as they knew it, in comparison to how it was prior to their sibling being ill. As a consequence 'healthy' siblings reported their feelings of isolation from family members and they felt a loss of their sense of self. Such feelings of loss are consistent with the work of Sloper (2000), who conducted research with siblings of cancer. Sloper (2000) suggests there are many losses that are encountered by the sibling which include; loss of certainty, loss of companionship of a sibling, not feeling valued, as well as having reduced levels of attention. Woodgate (2006) adds that as a consequence of the losses encountered, siblings of chronic illness are expected to care for themselves much more and do not want to burden their family with their worries because they want to protect them. They are committed to keeping their family together, despite their

enduring sadness along the disease trajectory. The study concludes for siblings needs to be addressed when they have a brother or sister with cancer as again they are identified as being unmet.

An alteration in family life that was also highlighted was the additional responsibility that siblings can be expected to take on (Hamama et al. 2008). Hamama et al. (2008) suggests that the additional responsibility that can be placed on a sibling when their brother or sister is chronically ill, can lead to role overload. Hamama et al. (2008) define role overload as being when the expectations of an individual outweigh the resources available to cope with the demands of those expectations, which can place the sibling under duress as it may be beyond their capabilities or beyond a time frame that they feel they can manage (French and Caplan 1973). Additional roles expected of the 'healthy' sibling can include becoming care giver's themselves, talking and listening to their chronically ill sibling and helping at home or in school. As a consequence it can impact on the wellbeing of the 'healthy' sibling.

A high level of role overload in siblings of cancer was reported by Hamama et al. (2008) and this correlated with the Novak and Guests (1989) indices of burden for role overload, which included time as a burden in terms of the expectation to engage in care giving. Developmental burden in terms of not being able to socialise with peers, physical burden in terms of being tired or having a headache/stomach ache and other reported physical symptoms were also identified in this study. Siblings suffering from physical/somatic complaints were also reported by Knecht et al. (2015). Social burden is stated in relation to one's feelings towards the care giving role and emotional burden as a consequence of the negative feelings the sibling may have in relation to the child receiving their care. Such feelings can be resentment, anger, aggression and jealousy. Role overload can impact on the daily life of the sibling, their emotional composite, and their relationship with their family as well as their scholastic/school activity.

Alderfer (2010) agrees that siblings of cancer have a poor quality of life in terms of their emotional and social functioning with family as well as their educational functioning in school. Bellin and Kovacs (2006) would concur with Hamama et al. (2008) as they also report the burden and frustrations of siblings in relation to additional responsibilities that they are faced with due to having a chronically ill brother/sister and they discuss how it impacts on their social world and ability to partake in external activities with peers. Therefore Hamama et al. (2008) suggest it is important to assess the sibling's ability to cope with new roles and tasks that can be expected of them.

Waite-Jones and Maddill (2008) concur with Hamama et al. (2008) Bellin and Kovacs (2006) and Alderfer (2010) in terms of alterations and adaptations that occur in family life, as they recognise the tension that can occur within a family and its impact on the sibling when they have a chronically ill brother or sister with the specific condition of idiopathic Juvenile arthritis. They suggest that this can lead siblings to experience feelings of heightened ambivalence towards the chronically ill child. Waite-Jones and Maddill (2008) suggest this can impact on their overall social wellbeing and development. A raised level of ambivalence can occur because siblings witness the emotional impact of the flare up's of the disease on their ill sibling and other family members as well as trying to cope with their own worries and concerns. Waite-Jones and Maddill (2008) categorise this as emotional contagion. They also suggest that siblings are subject to unfavourable treatment by their peers because they are associated with a sibling that has a noticeable physical disability and sometimes siblings do not want to be seen with their chronically ill brother/sister because they are different than their peers and themselves. Waite-Jones and Maddill (2008) categorise this as social contagion. As a consequence of this they advocate the need for support from extended family members for the sibling.

2.1.4 SIBLING EMPATHY AND MATURITY

A positive trait that was identified within the literature was the empathy and maturity that siblings exhibited when living with a chronically ill child within their family. Labay and Walco (2004) explored sibling relationships in terms of level of empathy and adaptation of children that had a brother or sister with cancer. Within their study they reported a correlation between the sibling's age and knowledge of the chronically ill child's cancer and their ability to externalise their empathy towards their brother or sister. They report that empathy scores were higher in girls in the study than in the boys. Labay and Walco (2004) suggest empathy to be a positive trait because it enables siblings to have a greater understanding of the need for differences in parental attention and privileges given to the chronically ill child. They suggest that it also places siblings in a position of maturity as they can have a higher level of empathy than their peers who do not have a brother or sister with a chronic illness.

Mulroy et al. (2008) sought parental views of siblings that had a brother or sister with the chronic conditions of Retts syndrome and Downes Syndrome. Parents reported positively in terms of the sibling level of maturity as they stated that their child was more caring, compassionate and considerate of their brother/sister. They also stated that the sibling had a greater appreciation of the value of health and the preciousness of life and they were patient and supportive members of the family. Mulroy et al. (2008) suggest that having a sibling with a chronic condition can build one's character as it provides development of personal skills and attitudes that may not be available to their peers.

Within the review by Knecht et al. (2015), they report that several studies including Alderfer (2010), Bellin and Kovacs (2006), Murray (1999) and Williams (1997) have identified that siblings living with a chronically ill brother or sister demonstrate what is termed as social competence with regard to their ability to communicate effectively, co-operate with others and demonstrate commitment towards others. Specific positive sibling

behaviours/traits identified were that of compassion, patience and empathy. Crucial to gaining social competence according to Knecht et al. (2015) is sibling security and certainty in relation to the situations that they find themselves in.

2.2 THE IMPACT OF CYSTIC FIBROSIS AND ITS TREATMENTS ON THE FAMILY

To provide greater context to the study, the impact of cystic fibrosis on the family is discussed below:

The focus of providing every day treatment for a child with a life limiting chronic illness such as cystic fibrosis can be extremely time consuming, burdensome and emotionally demanding for the whole family (Fidika et al. 2015). Alteration/adjustment in lifestyle cannot be avoided because the mainstay for treatments is in the family home and the parental role has to alter/fluctuate from being a parent to being a carer, due to the demands of their child's condition (Ward, Glass and Ford 2014, Barker et al. 2011, Williams et al. 2009, Mulroy et al 2008. Foster et al. 2001, Hodson et al. 2007).

With this alteration in role, parents learn to respond to their chronically ill child's needs and in doing so they gain an expertise in managing some complex treatment regimens. They also become more vigilant to their child's condition, which means closer monitoring in case there are deteriorations or new symptoms that need to be addressed (Smith et al. 2015, Knafl et al. 2013, Swallow et al. 2012, Barker et al. 2011, Williams et al. 2009, Foster et al. 2001).

As a consequence, caring for the child with cystic fibrosis can place many challenges on the family in terms of everyday family functioning due to the demands of the disease, which can cause increased stress and anxiety (Brucefors et al.2015). Relationship patterns can alter when a child is diagnosed with cystic fibrosis because the focus of attention surrounds the needs and priority requirements of the chronically ill child (Beacham and

Deatrick 2015). Family social worlds can change and family members can become isolated particularly because they are unable to mix with other families/children with cystic fibrosis because of the risk of infection (Wahab et al. 2014). Parents may be reluctant to leave their chronically ill child with others due to the fear that their child may become unwell or that treatments may not be adhered to appropriately. There may be a reluctance of extended family members or friends to look after the chronically ill child to allow parents some respite, because they may also worry in case the child deteriorates. For some families parental relationships do not survive and couples may choose to separate because the above demands can be too much to cope with which can cause further upheaval for all.

Brucefors et al. (2015) reports correlates between the cystic fibrosis child's quality of life and parental anxiety and depression, with fathers demonstrating a higher prevalence for depression than mothers. As a consequence Brucefors et al. (2015) suggests that there is a need for parental mental health to be monitored when they attend with their child for cystic fibrosis clinic visits. This is an important suggestion as Blubond-Langer (2000) suggests that children are sensitive to parental anxieties and concerns.

Another stressor that can be placed on the family is the financial burden of caring for their chronically ill child because a parent may be unable to work or may only be able to work part-time due to the daily treatment demands of the disease, particularly as the child with cystic fibrosis has to attend regular clinic visits or can require hospital admission if there is deterioration in their condition (Berge et al 2006, Rodrigues and Patterson 2007, O'Brien 2009, Knecht et al 2015). The ability of a family to deal with such challenges can be dependent on their ability to cope as well as the support mechanisms/systems that are available to them (Melynk et al. 2001, Swallow and Jacoby 2001, Wong and Heriot 2008, Smith et al. 2015).

2.2.1 HISTORICAL EXPLORATIONS OF SIBLINGS LIVING IN THE CONTEXT OF CYSTIC FIBROSIS

Historical literature surrounding perceptions and impact of living with a brother with cystic fibrosis is available (Turk 1964, Gayton et al. 1977, Harder and Bowditch 1982, Cowen et al. 1986 along with the seminal work of Bluebond-Langner from 1985 1991; 2000). However since these previous studies, there have been alterations in the disease trajectory as mentioned above in terms of knowing ones genotype, available treatments and an increased life expectancy with the disease no longer being restricted to childhood. Changes in lifespan can be seen in Bluebond-Langners (1991; 2000) work from the 1980's as she states that at the time of her study in 1985; 1986 the median age of life expectancy was then 19 years of age as opposed to 41 years, (mentioned in the cystic fibrosis section below). Therefore more recent literature was examined above in relation to chronic illness:

2.3 WHAT IS KNOWN AND NOT KNOWN AS A CONSEQUENCE OF THE LITERATURE REVIEW?

The studies above when examined collectively present a confusing and contradictory view of the impact on the sibling of living with a brother or sister with a chronic illness, in relation to the reports of negative and positive outcomes discussed. There is a predominant focus on quantitative methodology and limited opportunity for the sibling voice to be heard. The contradictory findings are consistent with historical literature that has explored the perceptions and impact on siblings and families when living with a brother or sister with cystic fibrosis (Turk 1964, Gayton et al. 1977, Harder and Bowditch 1982, Cowen et al. 1986, Bluebond- Langner 2000). There are no clear conclusions because siblings can have good days and bad days (Woodgate 2007), experience conflict and concern (Knecht et al. 2015) and they appear to be affected in different ways by living with a chronically ill child. It can be dependent upon many variables including their siblings illness, their understanding of the disease, as well as roles that are expected of them, available support systems and their ability to

cope. According to Knecht et al. (2015) a surrogate view of sibling's experiences is presented within the literature surrounding siblings experiences of living in the context of chronic illness, i.e. the views of parents, nurses and researchers rather than the sibling themselves, which can also add to the confusion, contradiction and distorted perception of the sibling experience.

A gap is identified in terms of the need for further research to provide a contemporary insight into the sibling's own experiences of living with a brother or sister with the specific chronic illness of cystic fibrosis, particularly due to the nature of the disease, changes in the disease trajectory and treatment regimens. The literature has identified that we do not know enough about siblings and the wider impact on families when living with this condition.

It was also noted within the literature that the sibling is often referred to as the 'well sibling' or 'healthy sibling' due to their absence of physiological illness, whereas it is suggested that some siblings do have psychological, emotional and behavioural affects due to the impact of living with a chronically ill family member (Wilkins and Woodgate 2007, O'Brien 2009 Knecht 2015). This highlights the need to explore the issue of the sibling being constructed in the illness context as 'well' and to challenge such binary thinking in relation to illness/wellness.

It is identified in the literature that there have been attempts made to provide interventions and strategies to help 'well' siblings of chronically ill children within the family (Murray 2001, Simms 2002, Essen and Enskar 2003, Bransetter 2008, Gursky 2007). However; on examination of these studies it would appear that the interventions were mainly short term and in some, children's views were not always actively sought in relation to their own needs. This is consistent with Knecht (2015) in terms of the limited voice of the sibling. Whilst the interventions provide some short term improvement for example; in reducing levels of anxiety or improving

their educational knowledge level regarding their chronically ill siblings illness, this does not appear to be enough to fully equip the siblings to cope and function in the context of their own world, with their own family, which can be very individual to each child. Their needs are not always fully addressed with care based on judgement and limited consideration is given on the issue of how this may impact on the 'well' sibling in later life (Bergemen and Wallace 1999).

According to O'Brien (2009) and Knecht et al. (2015) it is important that siblings are not forgotten and that their voices are heard so that they can state their needs, so that they can be met because having a chronically ill brother or sister can have an influence on their world due to many amendments and challenges that are encountered. This along with the sibling stage of development can also influence their sense of belonging, stability and ultimately their identity (Sharpe and Rossiter 2000, Coffey 2006, Wilkins and Woodgate 2007, O'brien 2009, Hamama 2008, Woodgate 2007). In terms of the child's stage of cognitive development, previous literature (Waite-Jones and Madill 2008) has suggested that adolescence can be a particularly vulnerable time for siblings, however Charlesworth, Wood and Viggiani (2011) suggest that middle childhood can also be a particularly challenging time for the sibling due to new changes in their social world also occurring.

Therefore children and families in the chronic illness trajectory can be a particularly challenging group to care for because a chronic illness such as cystic fibrosis can have an impact on the psychosocial and emotional wellbeing of the whole family including the sibling (Rodrigues and Patterson 2007). There is a need for more research and greater insight surrounding sibling experiences from their own perspective when living with a brother or sister with cystic fibrosis. This could help to inform strategies of family centred care that could be put in place to enhance sibling wellbeing (Knecht 2015, Smith et al. 2015).

2.4 ADVOCATING FOR FAMILY CENTRED CARE

Family centred care from a healthcare perspective is an evolving social construct that has been influenced by societal change, policy and health care agenda since 1950 (Mikkelson and Frederikson 2011,). It is a recognized concept that emphasises the use of partnership and negotiation when caring for children and their families. It is emphasized in the literature that it is fundamental that professionals working with children, plan care around the needs of the whole family and offer family centred care to help support family functioning. It is particularly advocated in children's nursing practice (Casey 1988, Nethercott 1993, Smith, Coleman and Bradshaw 2002, Tomlinson 2002, Franck and Callery 2004, Shields 2006, Shields 2009, Smith and Coleman 2010). However, even though this philosophy is widely acknowledged in healthcare practice, its use is subject to much debate (Shields 2009).

2.4.1 POLICY

Historically the concept of family centred care was not valued by health professionals with parents excluded from care because it was viewed that their presence would be detrimental to the health of the child (Shields and Nixon 1998). The emphasis was on caring for the physical wellbeing of the child, carrying out tasks and maintaining asepsis rather than considering their psycho social and emotional needs.

Earlier reports including the Platt report (1959), National Association for the Welfare of Sick Children in hospital NAWCH (1984) and the Court report (1976), informed policy and influenced a significant change towards family centred care, and advocated the importance of caring for the psychological/emotional as well as the physical needs of the child by allowing the family to have a greater presence in their care. It was also recognized that the needs of children in hospital are very different from those of adults, therefore the focus on care delivery needed to be more family oriented and parents were actively encouraged to stay with their child.

Policies have also been fundamental in transitioning family centred care philosophy into the present day because they advocate for children to be cared for by professionals who are trained with the appropriate knowledge and skills required to work with families. There is greater recognition for the wellbeing needs of children to be met to provide stability in their development and adjustment through childhood and their move towards adulthood in the key policy documents listed here: WAG (2004) Children and Young People: Rights to Action, DOH (2010) Achieving equity and excellence for children. How liberating the NHS will help us meet the needs of children and young people, DOH (2009) Healthy lives, brighter futures- the strategy for children and young people's health.

In contemporary practice the concept of family centred care promotes inclusivity and involvement of the family in the chronic illness trajectory, because the family is viewed as being a constant in the child's world (Shields 2006). Therefore maintaining family inclusion and having an awareness of their strengths and weaknesses when living with an ill child is suggested to improve health outcomes, inform decisions, as well as enhance child and family satisfaction in the planning and provision of care (Law 2003, DOH 2010, Smith and Coleman 2010).

This is congruent with the espoused family centred principles of; respect, dignity, collaboration, information sharing and acknowledging cultural and linguistic differences (Kuo et al. 2011). These principles suggest that any care provided should be in the context of the child and family's world. In doing so it should consider the family in their home and community environment, along with acknowledging their quality of life and daily activity. Kuo et al. (2011) discussed that joint collaboration had occurred with family and health care groups and included the American Academy of Pediatrics and the American Institute of patient and family centred care to formulate and agree these principles.

The American Institute of patient and family health (2012) are internationally recognised in advocating for patient and family centred care, they promote and provide training on key principles for implementation in practice throughout the States. There are no similar institutes in the UK, but some of the principles put forward earlier are recognised in UK policy plus other studies, which are integrated into health education curricular (Casey 1988, Nethercott 1993, Smith, Coleman and Bradshaw 2002, Tomlinson 2002, Law 2003, Franck and Callery 2004, Shields 2006, Shields 2009, Smith and Coleman 2010, DOH 2004, DOH 2010).

Whilst practitioners support the philosophy and espoused principles of family centred care and its use in education curricular, it is suggested that there is no available evidence to prove that it is effective in practice (Shields 2007, Klassen et al. 2008 and Shields 2009, Kuo et al. 2011). However a more recent update on a systematic review Shields (2012) adds that there is very minimal limited evidence of its effectiveness and even though there are some UK studies available, there appears to be a stronger influence of collaboration surrounding family centred care in America than in the UK (Shields 2007, Klassen et al. 2008 and Shields 2009, Kuo et al. 2011). This can impact on individuals practice and care of the family. It is also suggested that ongoing education sessions relating to family centred care are limited. Insufficient information and knowledge can lead to unmet needs as it would appear that there remains a gap between this ideology and the realities of integrating its principles into practice (Palmer 1993, Rennick 1995, Noyes 1998, Hutchfield 1999, Kuo et al. 2011).

A recent framework has been developed for use as a foundation to help improve parent and professional collaboration when caring for their child who has a long-term illness (Smith et al. 2015). The framework recognises the need to design services around child and family needs and is based largely on gaining parental perspectives but the use of the

framework is yet to be evaluated (Smith et al. 2015). However, in the meantime child health workers still require more specific information to help them gain a greater understanding of individual family members needs, including recognition of their diversity and cultural ideals (Thompson 2012). They also require greater clarity in how family centred care can be utilised in different environmental settings so that care can be facilitated at all levels (Shelton et al 1987, Kuo et al. 2011). Greater exploration of family centred care in the UK context also needs to be considered. These suggestions are important and could make a difference to the future practice of family centered care. However there are challenges faced in practice that also need to be examined and are discussed below.

2.4.2 CHALLENGES IN PRACTICE

Whilst the principles of family centred care are promoted it can be argued that professionals working in child health are faced with a challenge because these ideals are difficult to execute (Kuo et al.2011, Smith and Coleman 2010). Whilst, models of family centred care and inter professional frameworks have been suggested to guide implementation of the concept, in promoting communication, empowerment and or negotiation with children and their families (Department for Education and Skills 2005; 2003, Dunst and Trivette 1996, Dale 1996, Casey 1988, Smith 1995, Smith, Coleman and Bradshaw 2006). These frameworks can be considered outdated and Kelly (2007) found nurses do not like using them if they feel that they are being imposed upon them. It is also suggested that these models do not meet with the changing trends of health care provision that are driven by policy and evidence based practice (Sackett 2000, Kuo et al. 2011).

There is now a shift towards health care being provided in the home and carers taking on more specialist tasks that were previously synonymous with children's nursing (Coleman and Bradshaw 2010). This can add to the continual transformation of the family dynamic because taking on such extra responsibilities can lead to an additional burden on family members

and this was recognised by Lee (2004) as she raised the question “are we asking too much of families?” Some families have agreed with this and have felt there has been an assumption that they want to be involved in aspects of their child’s care all of the time or that they sometimes feel imposed upon (Coyne and Crowley 2007). A family member may feel obliged to act within a role that is expected of them, rather than exhibit their true selves and upset the family equilibrium in the chronic illness trajectory (Thompson 2012). This needs to be acknowledged for the purpose of this study because it is important to recognise family members as social actors within society and their influence on each other.

Conversely professionals do not always want to relinquish the locus of control to the parent, in what they consider to be their role and duties. They may not feel confident in caring for parents and want to concentrate more on the care of the child (Hughes 2007).

Therefore it is suggested that family centred care is not easy to instigate because the above models and frameworks can be open to subjectivity and interpretation, particularly in relation to what constitutes a family. Such varying perceptions can impact on the effective delivery of care and the realities of practice. However, taking into consideration the information within the literature review with the challenges faced for children and their families as well as having knowledge of the disease of cystic fibrosis, it is imperative that family centred care practices remain and that new insights are gained to help inform/improve these practices.

To enable greater understanding of the disease of cystic fibrosis, its treatments and its context in relation to this study, background information is provided below.

2.5 CONCLUSION

The literature review presented in this chapter had limitations due to the

lack of available contemporary studies specifically relating to siblings living in the context of cystic fibrosis. Where studies were identified, cystic fibrosis was incorporated alongside other disease groups. Where cystic fibrosis studies were available they were mainly historical and did not reflect the alteration that has occurred in the disease trajectory to represent present day practice. In relation to the chronic illness studies presented, there was limited primary focus on the sibling voice and this presents them as a marginalized population. There was also a limited focus on qualitative methodology and creative research methods. Therefore sibling stories are not fully captured.

Additionally the exploration of the literature in this chapter has identified some contradictions in relation to the perception of sibling emotional wellbeing, adaptation in family life and sibling social composite when living with a child with chronic illness. It has also discussed family challenges when living with a child with CF and has demonstrated a range of research methods being used. As mentioned previously quantitative methods have dominated the literature and sibling studies have been in the minority. The political and practice issues relating to the instigation of family centred care have also been considered and background information has been outlined in relation to the disease of CF. Whilst these insights provide an understanding of sibling and family worlds in relation to existing knowledge, it also highlights that there is still more that is not known in relation to a sibling living with a brother/sister with CF in the context of their family. The unknown elements in relation to the sibling voice, siblings in the context of family life, sibling wellbeing have been identified and highlighted as a need for further exploration. Therefore these elements will be drawn upon within the next chapter as they direct the research questions that are presented along with the creative methods that are used to elicit sibling narratives within their family when living in the context of CF.

“Would you tell me, please, which way I ought to go from here?”

*“That depends a good deal on where you want to get to,” said
the Cat.*

‘I don’t much care where’- said Alice

“Then it does not matter which way you go,’ said the Cat

*‘- So long as I get SOMEWHERE,’ Alice added as an
explanation.*

*‘Oh, you’re sure to do that,’ said the Cat, ‘if only you walk long
enough.’”*

Alice in Wonderland

Lewis Carroll,

3. CHAPTER THREE - METHODOLOGY AND METHODS CHAPTER

3.1 INTRODUCTION

This chapter takes the reader to the behind the scenes preparation that occurred in this study to enable the outcome of a dramaturgy production that will later be presented in the analysis chapters. Key research questions and a rationale for their choice are outlined. Discussions are presented in relation to the engagement and participation of siblings living with a brother/sister with CF within their family (n=10), using the methodology of narrative inquiry. There is also a discussion surrounding the use of a range of creative interdisciplinary methods that were used to enable the elicitation of the imaginatively expressed sibling narratives. These methods are presented as a bricolage to include narrative interview, visual creations/artefacts, and observations, along with metaphorical researcher reflexivity. The theoretical framework of dramaturgy (Goffman 1959) is presented as this is used as the 'lens' in which to view the social actions/interactions of the children within their cultural familial milieu in this qualitative study. The strategy for analysing over 200,000 words of data is also explained and the ethical considerations and challenges within the work are considered.

3.2 SECTION ONE - AIM, RATIONALE AND KEY RESEARCH QUESTIONS

STUDY AIM

The main aim of this child-focused research study was to explore the experiences of siblings living with a brother and/or sister with CF in the context of their family life. This focus was chosen because this participant group have been identified within the literature as a marginalised population who need to be given an opportunity to have their own voices heard (O'Brien 2009, Knecht 2015).

RESEARCH QUESTIONS

1. What are the experiences of siblings within their family in the CF trajectory?
2. How do siblings present themselves within their family?
3. What is the sibling's perception of their wellbeing when living in the context of CF?
4. How does their experience influence the perception of their needs?

3.2.1 RATIONALE

These questions were specifically chosen to address the gap in the literature in relation to the limited portrayal of the sibling voice that exists within contemporary research, particularly in relation to siblings living in the context of CF (O'Brien 2009, Knecht 2015). They provide a platform for these children to perform voice within this work is synonymous with the phenomenon of the being child as proposed by James et al. (2007). This was discussed in chapter two.

Remaining with the phenomenon of the 'being' child allows recognition of the child having some responsibility for its own construction as put forward by Wartofsky (1981), whereby the child can be given autonomy to have a say that can influence their being. Hughes and Ferguson (2004) suggest that this provides a new dimension to family life because this altered view of giving voice can provide diversity within the family as well as challenge traditional relationships. This view of the being child is representative of the new sociological studies of childhood as it diversifies from a traditional belief where the children's voice is not considered or recognised (James et al. 2007).

The phenomena of the 'being' child within this study is congruent with current policy agenda that advocates for the voices of children to be listened to and heard to enable healthcare services to progress as

expressed in Sir Kennedy's policy review (2010) The Royal College of Paediatrics and Child Health (2010) along with earlier policy documents (McLaughlin 2015, RCPCH 2015, DOH 2008, DOH, 2003,). This was a major drive and influence for me in conducting this project and in formulating the research questions stated above. The work is also supportive of James et al. (2007) who suggested that to have greater understanding of the being child in their experience of daily and to give voice, there was a need to research real children in their authentic worlds.

3.2.2 PHILOSOPHICAL/THEORETICAL POSITIONING

Positioning oneself within the work is considered essential when conducting a research study of this nature (Cresswell 2014, Mason 2002). Chuckry (1990) and Durant Law (2005) suggest ones positioning needs to address three philosophical areas to include, what exists? (Ontology), what is known? (Epistemology, Methodology, Logic) and what is valuable? (Axiology). Chuckry (1990) and Durant Law (2005) uses an analogy of 'the holy trinity' with reference to 'the father', 'the son' and 'the holy ghost' as an example when referring to the three philosophical positions, because when aligned together they create a philosophical alignment similar to that of 'the holy grail'. This alignment can be useful in informing the research inquiry in terms of formulating the research questions to be studied as well as in planning the methodology and methods to be used within the study in order to gain new knowledge and insights (Chuckry 1990, Durant Law 2005, Cresswell 2014).

In terms of this study my axiological position highlighting my values, beliefs, reflexivity and transparency in my journey in reaching this point as a researcher was outlined in chapter one. Epistemological concerns were raised as a consequence of the literature review in terms of what was highlighted as known and not known in chapter two and three. As a consequence the epistemological theory of narrative inquiry is used as the methodology to take forward this work and dramaturgy is used as the 'lens' in which to view sibling social actions/interactions in the context of their family world. The use of dramaturgy also links readily with social

construct theory and this links with the ontological view that siblings along with their family, in this study, are viewed as social actors engaging in constructed and co-constructed interactions on the stage set of family life. This draws together the 'holy grail' alignment/positioning that was necessary to enable the research questions above to be addressed (Chrucky 1990/Durant Law 2005, Mason 2002, Cresswell 2014).

Additionally as a researcher during this study it needs to be noted that my physical position was not always static as I was also a social actor/interactor within the work when engaging with siblings and their families, as well as taking on the roles of a dramaturge, bricoleur and reflector within this study. My interaction within these roles was as an adult, a researcher and a professional with a nurse/education background as opposed to being a child or family member. The roles of dramaturge, bricoleur and reflector listed above will be discussed later in the work.

Now that the positioning has been outlined, the theoretical framework of dramaturgy will be discussed, but first dramaturgy, as a word/concept will be explored.

3.2.3 WHAT IS DRAMATURGY?

Dramaturgy as a word can be defined as:

“The craft or the techniques of dramatic composition considered collectively” (Cardullo 2014 p3).

It represents a theatre, within which a play can be studied for its content, intellect, style, interpretive possibilities and its author (Cardullo 2014 p3). It is a concept that is concerned with performance, participation, social interaction and giving an impression that can enable the understanding of human being (Mehto et al. 2006, Lorek-Jezinska 2002, Borreca 1993, Buss and Briggs 1984).

3.2.4 DRAMATURGY AS A THEORETICAL FRAMEWORK

The framework of dramaturgy crosses disciplinary boundaries because whilst its roots are within the performing arts and drama theory, it is also recognised and used in literature, social psychology, political science, philosophy, anthropology and sociology (Goffman 1959, Goffman 1974, Burke 1972, Borreca 1993, Buss and Briggs 1984, 1993, Pettit 2011, Cardullo 2014).

From a performing arts perspective, Hay (2014) suggests that for a dramatic experience to make sense, a good production is needed whereby actors can be motivated to take the stage to perform a convincing role to an audience that is willing to watch. Hay (2014p75) continues in suggesting that from a dramaturgic perspective both the act and the production must have meaning to “make the drama work” as this is essential to the existential being of humans and of art. In the human performance of art the actor also needs to seek meaning for oneself through the consideration of knowing the how and the why of their situation (Frankl 1959, Hay 2014p75).

Knowing the how and the why is important but in the context of the performing arts, finding such understanding of the meaning of self, the act and the production can be a complex process because there is a need for harmonisation between the multiple actors required for the theatre. According to Hay (2014 p75) the articulation of the dramaturge (the playwright) can be helpful in this process of meaning making for the artists and the audiences, so it is essential that they (the artists) are involved in their work as well as their meaning seeking journey because as Hay states;

“Every production is a quest” (Hay 2014 p75)

The above perspective is synonymous with this thesis because this is a creative participatory research production that has drawn upon the

theoretical perspectives of Goffman's dramaturgical framework (1959/1974) whereby he provides a metaphorical theory that life is a theatrical play in which actors take the stage to give a group or solo performance (Buss and Briggs 1984). These interactive performances can enable the portrayal of a united impression to the audience in terms of how the actors themselves want their image of self and their word to be perceived Goffman (1967). Thus Buss and Briggs (1984 p1311) compare individuals to performers who portray a certain character through their ability to use their acting skills, as well as demonstrating their desire to use those skills.

According to Kivisto and Pittman (2013) individuals' impressions can be conveyed through a multitude of props including dialogue, gestures and artefacts to present an innovative actuality for the audience to think about and draw conclusions on. Kivisto and Pittman (2007) suggest that Goffman's theory of dramaturgy is concerned with the micro-level of interaction of human experience as opposed to generalization of the human condition. Lorek-Jezinska (2002) suggests such interaction should be recognised as a continuum where people interact at different levels as opposed to it being an on/off situation (i.e whether that be as an observer or participant). This is a stance that also connects with concept of social constructionism whereby individuals are viewed as being social actors and creators in society, as well as being a social product themselves (Burr 2015, Gergen 1994, Gergen 1985, Berger and Luckmann 1966).

In this work, using the dramaturgical framework has enabled the exploration of the front stage, back stage and role performances of children living with a brother and or sister with cystic fibrosis within the context of their family to allow unique insight into their worlds. It has provided a 'lens' that has enabled me to explore the key questions presented below and provided a framework on which to interpret the collected data.

3.2.5 THE ROLE OF THE DRAMATURGE

Considering Cardullo (2014 p6) and Katz (2014) performing arts/ theatrical perspectives of the dramaturgic role whereby a dramaturge is referred to as “the playwright” or the “maker of plays” was essential for preparing the research study doing the field work, working with children and their families as well as interpreting, editing and finally writing this thesis. Being a dramaturge has a duty bound role in preparing a text for performance, advising the actors, as well as editing, interpreting and reordering the scenes to create a final production (Cardullo 2014). In order to achieve a finalised production an underpinning level of knowledge, skills and experience is required according to Katz (2014 p13) who suggests that the dramaturge must have a “critical sensibility” as well as the ability to write, do scholarly research and possess a thorough knowledge of the dramatic repertoire to be presented. Hence being the dramaturge was interwoven with my role as a researcher/reflector in engaging with children and their families. Part of my own critical responsibility was to choose an appropriate design for this research study; therefore a qualitative research design is presented.

3.3 SECTION 2 - QUALITATIVE DESIGN

In considering the epistemological and ontological position of this work a qualitative research approach was selected in order to explore and answer the above research questions. Qualitative research can be differentiated from quantitative research, as its focus is not on the collection of numerical data, but instead on the collection of a rich data set that can be used to ensure thick descriptions of evidence that can be collected from interviews, observations and artifacts (David and Sutton 2011).

Choosing a qualitative design can enable an inductive approach to the research as well as encourage in depth explorations of contextual experiences, views and histories, to allow a persons story to be captured (Spencer 2003, David and Sutton 2011). It promotes greater openness in the study in terms of formulating research questions as it allows flexibility and fluidity not just in the questioning of participants, but also in the

research process as a whole (Mason 2002). What is important in this process though is to ensure sensitivity and thoughtfulness in choosing appropriate methods that will enable questions to be answered, so the meaning of data can be explored as well as understood.

Mason (2002) suggests it is not possible to provide a concrete research design in advance of conducting a qualitative research study because of its exploratory approach. A qualitative design is therefore removed from the idea of pre conceptions and a priori strategic planning because it is driven by the sensitivity of the contextual situations experienced as well as the data being collected (Mason 2002).

However Butler-Kisber (2010) advocate for transparency and trustworthiness when engaging in and presenting qualitative work and suggests a trustworthy research design should be outlined as well as transparent researcher reflexivity. Applying both should enable subjectivity for the participant and researcher voice to be heard. The specific qualitative approach/methodology that has been chosen for this study is narrative inquiry. The rationale for this choice as well as the theory linking to this methodology is presented next.

3.3.1 METHODOLOGY - NARRATIVE INQUIRY

Narrative inquiry was chosen as the methodology for this study as it sits within a constructivist framework as well as having a congruent link with dramaturgy (Engel 2005, Goffman 1969, Bamberg and McCabe 1998, Reissman 2000, Langellier 2001). This link between narrative and dramaturgy enables a story to be told with a greater emphasis on the role performance of the actors within the narrative itself, as narratives explore social situations as well as highlight characterisation within drama scenes that are presented (Bamberg and McCabe 1998, Reissman 2000). It is through the reciprocal engagement in stories and scenes between a narrator and a listener/audience that the performance of identity occurs although the performance may be one of preference to provide a wanted

impression (Langellier 2001, Goffman 1969). Bringing together narrative and drama is an approach that is advocated by Richardson (2015).

Narrative Inquiry itself has been used and advocated in previous studies by Reissman (1993) Mishler (1986), Bell (1999) and Chase (2005). Its roots have dated back to Aristotle's exploration of Greek tragedy (Reissman 2008), as well as noted in a multitude of disciplines including literary study, anthropology, folklore, psychology, sociology and nursing (Reissman 2002, Holloway and Freshwater 2007, Reissman 2008).

The use of terms narrative and story telling are viewed as synonymous in the literature and can be elicited from a variety of media (Freshwater and Holloway 2007, Butler and Kisber 2010). It is through narrative that a story can be told about daily life in a verbal or written form. It is where patterns of a person's experience of places, spaces and events can be recognised within the time span of a past, present and future. Narrative will provide temporality and provide the listener with the narrators' interpretation of their own view of a story (Holloway and Freshwater 2007). To provide meaning through a process of reflection and allowing an inter relatedness between physical and psychological knowing (Bruner 1986). Reissman (2008) acknowledges the importance of the sequential nature of the narrative told and its consequences for future actions and meanings for its audience.

Therefore narrative inquiry allows a contemporary approach to research whereby the subjective, relational and contextual nature of inquiry can be explored. Butler- Kisber (2010) suggested that this form of inquiry allows a move away from numerical methods of research whereby it is difficult to explore the complexity of the human relationship experience. Considering this approach when researching children can be beneficial in order to explore their worlds, that are considered to be private, imaginal, and uncertain as well as socially embedded (Bruner 1990). Engel (2005) promotes the exploration of children's narratives because of the insightful

lens that they offer in understanding their contextual world through the enunciation of their perspectives and feelings.

However it is important to be aware that children may narrate the words of others, which can generate additional power in one's understanding of interaction and socialisation (Kupfer 2011). Bakhtin (1981) would add that in taking on the words of others, the words still belong to the person speaking because they have used the words with their own expressive intention. As a consequence this can bring additional value to the content of the dialogue presented. It is also important to be aware that children's responses can be emotionally laden or difficult to express, so children may narrate through a metaphorical stance or they may demonstrate evasiveness in their demeanour (Rogers et al. 2005). This was something that I encountered within my research journey as can be seen in the findings chapters of the work.

Historically Labov and Waletzky (1967) suggest that narratives enable the sharing of the oral version of an individual's experience but in recent years narrative can also be captured in interactive performances as well as the spoken word (Reissman 2008).

Allowing creativity on the continuum of narrative along with performance observation was essential in moving forward with this work to generate data for collection, whilst maintaining sensitivity in stepping into the worlds of the siblings in their family lives. Being creative in the narrative world is acceptable as stories can be generated in different ways (Reissman 2008). An example can be seen in the work of Myerhoff (1978) that generated tales of the experiences of elderly Jews in Venice. Myerhoff (1978) used a combined approach of her own observations along with poems and stories to formulate powerful chronicles of their lives (Reissman 2008). For my own work with a child focus in mind, I chose to use visual methods to elicit their stories that were told during our narrative interviews. Borland et al. (1998) advocate for such creativity and Balen et

al. (2001) suggest personal interviews enable the generation of specific, individualised information regarding children's experiences.

Hence the approaches of narrative inquiry through creativity and performance observation to generate data were seen as appropriate elements for this work, to provide a humanistic stance where the individuality of each child can be recognised. The approach also enabled active participation of the non-CF siblings to be promoted within the research trajectory to maintain inclusivity and to address the power imbalance that can occur in the research relationship. Promoting active participation and autonomy was fundamental to the project as it is congruent in adhering to the UN Convention Rights Of The Child (1989), Matutina (2009), Cocks and Adams (2012). Other key policies also stress the importance of involving children and families in research as it moves away from the pretence of the child being able to have a voice, where there is a simulation of involvement of children but their views are not represented in healthcare decisions (Hart 1997, RHPCH 2005).

This eclectic methodological strategy using a narrative methodology is referred to as a bricolage (Denzin and Lincoln 1998). Denzin and Lincoln (1998) refer to the researcher who utilises a multitude of methods as a bricoleur. The role of the bricoleur and the use of bricolage was open to much debate within the literature, but it appears to have gained popularity in more recent years and has proved beneficial for gaining qualitative research data (Denzin and Lincoln 1998, Friedman 1998, Mcleod 2000 and Palmer 1996, Levi-Strauss 1969, Kincheloe 2001, Denzin and Lincolns 2000, Kellner 1995, fischer 1998, Madison 1988, MCarthy 1997). Some of the perspectives of these authors are discussed below.

3.4 FROM DRAMATURGE TO BRICOLEUR: TAKING ON A BRICOLAGE

Earlier on in this chapter I presented my role as the dramaturge but an adage onto this role in my researcher capacity was that of bricoleur. A bricoleur is a term used in the French language to refer to a qualitative

researcher or crafts person who uses multiple methods, media, strategies, practices, resources and tools on which to explore and solve contextual problems, questions or jobs (Levi-Strauss et al. 1998, Denzin and Lincoln 2000).

Bricoleurs can be criticized for being a “Jack of all trades” (Denzin and Lincoln 1998) and perhaps master of none as they are seen to cross interdisciplinary boundaries to achieve their desire. Critics such as Friedman (1998), Mcleod (2000) and Palmer (1996) suggest that working across disciplines in using bricolage is shallow and results in the researcher not knowing enough about a single discipline of research. Levi-Strauss (1969) would advise for such an approach to be avoided because they refer to it as cutting and pasting things together as if piecing together left overs.

Having now used the interdisciplinary concept of bricolage I would argue against the “Jack of all trades” criticism because I have gained a wealth of experience from using multiple methods. To stick with one discipline of research method would have meant a linear perspective would have been taken, which would not have been suitable for my work as it would not have enabled flexibility and creation within the research process. This was something that was necessary for engaging the non-cf siblings in this participatory project. Using an interdisciplinary approach proved beneficial as it allowed the generation of rich data. For me using bricolage not only opened my world but that of the research participants as they were given a freedom of expression to enable an impression in relation to their acts, performances and creations that could not have been predicted. This brought an aesthetic flare to the project. Denzin and Lincoln (1999 P4) recognized this artistic craft of using bricolage as they refer to bricoleurs as “quilt makers”. This term made me reflect back to some earlier work that I read when I was doing my masters degree some years ago. That was when I was exploring ways of knowing and Titchen (2000) referred to using different forms of knowledge as a tapestry. For me as you will see in the discussion chapter later in this work using bricolage enabled the

formation of a mosaic that captures the portrait of the siblings as a consequence of the methods used.

Despite the critics above that are concerned with the blurring of disciplinary boundaries, Kellner (1995) and Kincheloe (2001) advocate for the use of bricolage as they suggest such an approach allows new knowledge to be sought through the synergy and merging of methods. They refer to it as a multi-vocal approach that serves to create a deeper level of analysis of data. Both of these authors add that to stick with one research method is liminary and univocal as they suggest that removal of 20th and 21st century traditionalised disciplinary method demarcations is now acceptable. However Kincheloe (2001) suggests that to avoid superficiality in ones own research, the interdisciplinarian needs to have a greater understanding of the knowledge bases of the methods used in relation to their respective disciplines.

In relation to my study the methods chosen was reliant upon the research questions to be asked and the population to be studied. Using a multi method stance that allowed participation, flexibility, creativity and discourse was a substantiated decision that has generated a greater robustness to the research. It adds to the validity of the work as is generates wider ontological insights of sibling experience particularly as they were being studied in the family context and the two could not be separated from one another because that is their lived world. A single method may not have captured such rich ontological insight. Morawski (1997) recognises such connectedness of context in relation to ones individual, cultural and socially constructed lives.

3.5 PRESENTING THE BRICOLAGE: A CREATIVE REPERTOIRE OF METHODS

3.5.1 NARRATIVE INTERVIEW

The narrative interview itself is a collaborative opportunity whereby the researcher and the researched are active participants that both produce meaning when they are placed together in an interactive dialogue based on a stimulus/ response model (Mishler 1986). The open- ended nature of the narrative interview is congruent with modern ethnographic methodology as the narrator reports upon the events encountered (Gubrium and Holstein 2002). The researcher allows the participant to tell their story in their own sequential way to allow the discovery about a particular phenomenon Reissman (2008).

3.5.2 VISUAL CREATIVE METHODS TO ELICIT NARRATIVE

The term creative research can be used to encompass the merging of arts methods and narrative as such an approach has become more widely recognised and accepted in the research world (Bagnoli 2004, Reissman 2008, Leitch 2008, Butler-Kisber 2007, Bagnoli 2009, Lomax 2012a, Lomax 2012b, Lomax 2015, Mannay 2015). This is an important recognition because not all children are able to express their voice to tell their stories through verbal means, for some they require a different media that allows them to impart their views (Thomson 2008, Holliday et al. 2009). With this in mind using visual methods provides a way in which to engage children as participants holistically, creatively and practically within the research process (Shaw et al. 2011 and Whiting 2015). As it is through the promotion of creativity that children can be given the freedom to express their perspectives through meaningful activities that generate the imagination. Through creative activities they can gain an identification to enjoy and feel completely involved (Fury et al. 1997, Anning and Ring 2004, Thomson 2008). Such creativity and inclusion add to the narrative inquiry process as creativity induces a powerful ripple of significant unfolding stories magnified through image (Leitch 2008, Vygotsky 1978). Not only can image form a story, but a story can form an image. This dual dynamic allows a synergistic way for children to consciously frame their

existential self as well as expose the unconscious, unspoken, private, previously invisible, unacknowledged self (Leitch 2008).

This method provided a rich participatory research experience in my own study because children were invited to be the narrators of their own work as suggested by Leitch and Mitchell (2007). Other authors have also engaged children in the interpretation of their own visual creations (Bagnoli 2004, Dockett and Perry 2005 and Dreissnack 2006, Coad 2012). Clark and Ungerer (2007) suggest this is innovative and creative way of gaining information in relation to children's lived experience. According to Coad (2015) its use can provide a valuable contribution within health and social science. Hill et al. (1996) recommend creative approaches when studying those situated in middle childhood and Culling (1988) adds it is important to give children such an opportunity because they may be unable to place worries into words. The visual methods that children in this study engaged in were creating pictures, drawings, collages and photographs.

3.5.3 OBSERVATION

Observation is a recognised and widely used method of data collection whereby the researcher observes participants in their natural setting and they can also engage in the context of the social situation (Spradley 1979. Spradley 1980, Mulhall 2002, Oliver 2010). The amount of researcher interaction can be variable as it is dependent upon the situation that they find themselves in, the participants recruited as well as the nature and design of the research project itself (Oliver 2010). What is important about using this method is that it enables the researcher to gain a greater understanding of participant's perspectives in relation to the cultural dynamics of their world. It allows for people's stories to be encapsulated not only through their oral narration, but also through observation of their performance (Berns 2013). Butler (1998) refers to performance as the performativity of idiosyncratic acts that are repeated to represent embodied identities that reflect one's values and beliefs. Searle (1969)

cited in Butler Kisber (2010 p137) also acknowledge the performance in all language because of its verbal intent.

Both of these perspectives bear significance to this work in relation to the observation of narrative spoken and the performance of acts witnessed. This accumulation of information through observation can be captured in the writing of detailed field notes so as to generate rich data (Spradley 1979, Spradley 1980).

3.5.4 RESEARCHER REFLEXIVITY

Within this study it was important to consider my own situated self when visiting children and families within their homes to ensure self-awareness and transparency within the research process (Hollway and Jefferson 2007, Watts 2009). Researcher reflexivity enabled me to separate my own voice, thoughts and feelings from that of the participants through writing reflective notes as well as engaging in reflective discourse with my supervisors. It enabled a conscientisation of my existential being when out in the field and in writing up notes and transcriptions. Some of my reflections were written and performed with a metaphorical stance to enable me to process my own sense of being in terms of my development and progress in the research trajectory and are presented within the findings chapters of the work.

Prior to taking this study forward an appropriate sample size needed to be considered. Section three will discuss the sample and recruitment strategy prior to discussing the methods applied in this study as well as the approach to data analysis.

3.6 SECTION 3 - SAMPLE AND RECRUITMENT STRATEGY

3.6.1 SELECTING A SAMPLE SIZE AND PARTICIPANT POPULATION

In qualitative research the emphasis is to focus on the quality of information gained rather than the quantity due to its exploratory nature and this can influence the choice of sample size to be selected (David and Sutton 2011). Morse (2000) suggests that the type of study, the topic area

as well as the study design can also be influential factors in selecting a sample. Mason (2002) would add that this can also include the consideration of data sources to be accessed e.g. people and settings. Both David and Sutton (2011) and Morse (2000) agree that in qualitative work a smaller number of participants are required because large amounts of data can be collected that will provide enough insight in to issues being explored. They suggest that saturation of data can occur when participant responses/behaviours become predictable and this is also a consideration when selecting the sample size. Mason (2002) adds that a major question that the researcher should ask is whether their proposed sample size will enable a sufficient amount of data to be generated to make meaningful comparisons between participant data collected, in order to answer the research questions that have been set. She suggests that sometimes the final sample size may not be able to be stated at the beginning of a qualitative study because a researcher may have to wait until the data provides a more meaningful picture, which is itself reliant on the social world being explored.

The type of sampling selected is important as the sample size because the two choices can be interdependent and can influence the amount of data that can be collected (Oliver 2010, Mason 2002). Oliver (2010) differentiates between probability/random sampling and non-probability/purposive sampling. He suggests the former to be where a member of the population has a known probability of being selected and remarks that the population can be selected randomly from a list of numbers. This type of sampling can be useful for scientific positivistic research. Whereas the latter is more appropriate when key informants are needed because these participants have relevant characteristics, knowledge and/or experience that can be helpful to the research questions that need to be answered (Emmel 2013, Oliver 2010, Vogt 2005, Jupp 2006).

Based on the above information a table was formulated below to help guide the decision in choosing the sample size and type of sampling to be

used for this study. The table draws together the questions raised in the work of David and Sutton (2011), Oliver (2010), Mason (2002) and Morse (2000).

Table 3: Sample size questions and answers

Sampling choice questions	Answers/decisions made
What type of study?	Qualitative
What is your study methodology?	Narrative inquiry
What is your topic area?	Non cf Sibling experience/ family
What data sources will you access?	Children within the context of their family
What is the focus of the research questions?	Sibling experience when living with a brother or sister with CF
What are the relevant characteristics for the study population?	Siblings, children in middle childhood, family, willing to participate in the study, must have knowledge and experience of living with a child with cystic fibrosis
Can the study population be compared for meaning making and generate data?	Yes with multiple visits
How many research visits for each participant?	Four visits – to enable the generation of rich data
What type of sampling has been chosen?	Non-probability purposive sampling
How many participants chosen?	10 siblings without cystic fibrosis

As can be seen from the table above, the study sample that was recruited for this work was ten children without a diagnosis of cystic fibrosis who were living with a brother and or sister with the disease. The age group chosen was representative of middle childhood with the aim being to recruit non-cf siblings within the age range of 8 to 12 years.

Exploring the literature on middle childhood enabled this decision to be made in advance of the research study-taking place. However there was a slight deviation from this on application of the research with two children being age seven at the first research visit and then they had an eighth birthday before the second visit. These two children were what I would call on the cusp of my recruitment window. They were both of the cognitive ability/articulation of an eight year old and so were accepted into the study.

All ten siblings' were recruited in the context of their family worlds and were informed that the primary research space would be in the home. However one sibling chose for his final visit to be at the swimming pool and I met the family in the café area of this facility, as being accommodating the needs of the family was essential.

In terms of recruitment I did not encounter any problems in gaining participants for the study. This is contrary to Hammersley and Atkinson's (1995) suggestion that how gaining access to participants can be problematic. My enthusiasm, motivation, quiet determination as well as my proactive endeavours in taking the study forward may have been responsible for this.

3.6.2 NUMBER OF SIBLINGS RECRUITED.

Two siblings were recruited through snowballing/word of mouth.

One sibling was recruited from attending a cystic fibrosis trust event.

Seven siblings were recruited from one health board that incorporates two hospital sites.

My total was ten, which amounted to 100 % recruitment being achieved.

3.6.3 SIBLING GROUP: MIDDLE CHILDHOOD

This age group was specifically chosen, as it is representative of middle childhood and is congruent with the discussion in chapter 2. Additionally, Fivush and Nelson (2004) suggest that children below the age of seven have a limited autobiographical memory, therefore limiting their ability in narrative engagement and their understanding of self. Mannay (2011)

found the middle childhood range commencing at eight years as most suitable when incorporating narrative inquiry into a study.

Table 4: Outlines the demographic of the siblings recruited

Family	Child pseudonym	Age	Number of CF siblings	Other non cf siblings	Parental Marital Status	Location
1	1.Josh	9	1 (younger)	2	Mum has new partner	Town
2	2.Erin	10	1 (older)	1	Single parent	Town
3	3.Charlotte	11	1 (younger)	1(Molly)	Married	Suburb
3	4.Molly	7 at first visit / 8	1 (younger)	1(Charlotte)	Married	Suburb
4	5.Raff	7 at first visit /8	2 (older)	0	Married	Coastal
5	6.David	8	1 (younger)	2	Single parent	Valleys
6	7.Elinor	8	2 (1younger) (1older)	0	Married	Suburb
7	8.Hattie	8	2 (1 twin) (1 older)	1	Married	Suburb
8	9.Nancy	8	2 (1older) 1 younger	0	Married	Valleys
9	10.Adam	8	1 (younger)	0	Married	Valleys

3.6.4 ADDITIONAL RECRUITS

My posting on the CF research forum generated interest from one parent of a child and a sibling with CF. A mother emailed and then phoned me as she wanted to tell her story of her experience of having a CF child and a non-CF child. The narrative can be found within the appendices (Appendix 23) of the study as it was not included in the analysis and was not part of the inclusion criteria of the study as it was solely a parental voice. However I felt I had a moral obligation to listen to the parent and to include their work as it remains a powerful story and it represents a parent's plight.

I also received an email from an older sibling (age 22) who wanted to tell her story and share her experience of living with a brother with CF. Her story reflected back to a time when she was 13 years old when her brother was diagnosed. I have included her voice in the third chapter of findings as a guest appearance because her story has implications for siblings in the future and I felt a moral obligation to share her powerful emotive voice and the influence of CF on her journey in life.

3.7 IN THE FIELD: BRINGING THE PROJECT TO LIFE TO GENERATE DATA

Initially entering the field to attend CF clinics and to visit siblings in their homes evoked a feeling of elation as it was a time of excitement and anticipation, because I had finally reached a new stage of my project moving from the preparatory phase of setting up the work and gaining ethical approval. Moving through each stage of the study felt like a new milestone achieved, but what was special about moving into the field was that my research plan was finally going to be brought to life. I had no idea what to expect in what lay ahead in spending time with the siblings but what I did know was that I was heading into a transformational journey.

I introduced the work to the children and their families as the 'listen hear' project. The title was aptly named so as to promote the voice of the child and to give the message that I was going to be present in their world to not

only listen, but to really hear what they were trying to tell me through their verbal or non verbal performances. There were four stages to the work with the formation of the non-CF sibling creations and narratives being guided by two specific topics listed below:

- 1) Me and my family
- 2) Future selves

The first topic was chosen to allow for exploration of the sibling perception of their identity within the family. The second was designed allow for the exploration of sibling future needs and concerns. Rawson (2009) discussed the importance of considering the future perspectives of siblings, because they can have worries and feel burdened with responsibility. When faced with a brother or sister with a disability it can infringe on a siblings own time and their plans for the future. Rawson's study (2009) was primarily with adults and was focused on learning disability, but the above key issues can also be relevant to child siblings of chronic illness and are worthy of further exploration.

The two topics were chosen to link in with the objectives of the study in relation to the research questions in order to gain the siblings perspective of their experiences and needs within the family as well as to provide an insight into how they present themselves in their family world. Using the two topics also provided an opening for discussion, which Balen et al. (2001) would advocate as a useful form of icebreaker to allow the beginning of rapport building when working with children. The aim was to promote the non-CF siblings active engagement in the research process right from the start by providing a topic of interest with which they could identify. The topic areas were to be explored over four one hour visits with the non-CF sibling in the context of their family and in their home environment. Between the four visits the siblings were given time to think about the project topics and/or prepare their creations and or performances. The siblings referred to the gap phase between my visits

as homework time. The project stages are outlined in **Table 5**:

Project stages	Activity	Engaged Methods
Stage 1 Visit 1, 1 hour	Meeting the sibling and their family	Observation/participation
Break Negotiated time lapse between visit 1 and 2	Homework: Preparing or thinking about getting to know you activity/ picture	Participant led (Researcher not present)
Stage 2 Visit 2, duration 1 hour	Getting to know you and discussion to prepare for the picture/creation	Observation/participation
Break Negotiated time lapse between 2 and 3 rd visit	Homework: Preparing picture/collage/creation	Own choice / participant led (Researcher not present)
Stage 3 Visit 3, duration 1 hour	Presenting creation 1 'Me and my family' Discussion re preparing for next activity of 'future selves'	Narrative interview / visual/ creative elicitation
Break Negotiated time lapse between 3 rd and 4 th visit	Homework: Preparing next activity, creation/ picture/collage	Own choice. Participant led (Researcher not present)
Stage 4 Visit 4, 1 hour	Presenting creation 2 'Future selves'	Narrative interview /visual/creative elicitation

This structured format was used to guide the activities, however this was not set in stone as it allowed for flexibility, which was essential for the data collection process. The aim of my first visit was to introduce myself to the family and to talk about the project, the rationale and expectations in terms of what was required of the non-CF sibling within the context of their family

life. It was also at this visit that consent was gained from the siblings themselves. Whilst parents had consented in allowing me to visit, it was essential to make sure that siblings wanted to be involved and that they were not doing so under any duress or misconception of what the study was about. Gaining their written consent was also necessary. The four visits are outlined in more detail here:

3.7.1 VISIT ONE - INTRODUCTIONS

The first visit focused on introductions between the researcher and the family members in terms of the nature/rationale for the study as well as gaining consent from the siblings/family to partake in the study. During these visits families were very welcoming and they readily engaged with the researcher in interactive dialogue in relation to their child with cystic fibrosis and aspects of family life.

It was at this first visit that each of the sibling participants were asked if they would be willing to independently create a picture/collage or use photographs to represent their own visual impression and interpretation of their world in relation to the aforementioned topics 'me and my family' and 'future selves,' prior to them having two narrative interviews on two separate occasions. The children decided themselves what their form of creation would be and they informed me of the material that they needed to help them to formulate their pictures. Some of the children specified wanting to use their own resources because they already had these at home. I had wanted to make sure that there was no cost incurred to any of the families for the child making their pictures and I offered to pay for any additional outlay and I stated this in my introduction to the project materials. During this early stage I was acting as a facilitator of the task at hand, which was something that I was used to in relation to facilitating the use of creative media as learning and teaching methodology with undergraduate students.

Below is a photographic example of the materials provided for their proposed activities;



Flexibility and choice was key in using this creative bricolage for data generation with these child participants. Their own views were respected as children did not all choose the same visual media in which to elicit their narrative voice and performance.

3.7.2 BREAK ONE: HOMEWORK

The term homework is used here because that is how children in this study referred to the time break in preparing for the next visits.

During the period of time between visit one and visit two, siblings were asked to think about an activity that they would like to do or prepare for in advance of the second visit. I explained how I would like to know more about them as a person and what it is like being them in their family. The choice of activity was there's.

NB: The break period for all was flexible and children and their families negotiated a time frame with the researcher. The challenges faced in terms of the break time are discussed later in the work.

3.7.3 VISIT TWO - GETTING TO KNOW YOU

The second visit focused on the researcher getting to know the sibling within the context of their family world. Siblings were given the opportunity

to spend time with the researcher and they chose how this time was spent within their home. The children chose activities for me to see or to be involved in which included the observation of performances of singing a song, dancing, playing a musical instrument, doing gymnastic moves as well as playing games, making a bracelet, doing a jigsaw or showing family photographs amongst other activities. The getting to know you visit enabled the sibling to begin to share their stories of their world and their experiences through their own chosen creative expressions. Sibling interactions with their family members were also observed in this visit. The visit also focused on preparing the child for their next activity in terms of making sure that they understood what they were required to do for their picture/collage/visual creation that would be used to elicit the narrative interview. Siblings were eager to do their creative pictures and were excited about being asked to participate in the study.

The picture below is of two dolls, which Hattie, one of the siblings presented during my visits. Each doll has been made especially to represent how Hattie and her twin sister who has CF look. They have been individually designed to represent their unique personalities. Hattie is the one dressed in pink.



3.7.4 BREAK TWO: HOMEWORK

During this period of time siblings focused on their creative activity in relation to their picture for the topic 'me and my family'. They were aware that they would be asked to share and talk about their picture, at visit three.

3.7.5 VISIT THREE - TALKING ABOUT THE VISUAL CREATION/ RECORDED NARRATIVE INTERVIEW 1: ' ME AND MY FAMILY'

During this visit siblings presented their visual creations and talked about what their picture/collage represented. Media presented by the children during the narrative interview visits included picture drawing, collage formation, combined collage and drawing as well as using photographs, presenting artifacts such as toys, poems and psalms. These creations gave them the freedom of expression that enabled them to engage in narrative discourse.

The discussion was primarily led, by the sibling and I used prompt questions that were relevant to the sibling's dialogue as well as being pertinent to the research questions to be answered.

The visit was not set in stone so to speak and siblings did choose to introduce other creations/ activities that they wanted the researcher to know about them and their family. Flexibility and adaptability were important because some children did not want to spend too much time on their picture, whereas others did.

Offering choice is accepted and advocated when engaging participants in the research process and it also can help to obliterate any power imbalance, to enable research aims and objectives to be met (Harcourt et al. 2011, Shaw et al. 2011, Matutina 2009, Thompson 2008). Giving responsibility to the participant in directing their own contribution in the research trajectory can encourage their participation and their engagement, as well as affirm their assent within the process (Dockett et al. 2011). As stated earlier, some children do not feel able to impart their

views verbally all of the time and for one child most of the time, hence; this creative bricolage provided a meaningful and enjoyable experience for the children in this study because they will felt more actively involved in the research. It also provided them with an opportunity to think about and reflect on their experience prior to the narrative interviews.

Toward the end of this visit, siblings were prepared for the next stage of the research that would focus on 'future selves'. For some children, they requested to just talk rather than present a visual creation because they felt comfortable to just talk. Some of the siblings talked about their 'future self' within visit three.

3.7.6 BREAK THREE: HOMEWORK

Siblings prepared for visit four in either a creative activity or thinking about what they wanted to talk about at the next visit.

3.7.7 VISIT FOUR: RECORDED NARRATIVE INTERVIEW 2: TALKING ABOUT 'FUTURE SELVES'

The focus of this visit was for siblings to talk about how they might see themselves in the future as an adult. Most of the children chose to not do a visual creation for this exercise and instead chose to engage in dialogue surrounding the subject instead. Due to sibling choice and flexibility within the study, children chose to diversify from the topic area and engaged me in dialogue and activities that were temporal to the moment.

3.8 CHALLENGES:

3.8.1 SETTING THE PACE FOR THE STUDY

The children set the pace of the study in negotiation with their parents and me. As they were asked how long they thought they would need to complete or prepare their creative repertoires as well as when would they like me to visit again. My initial time frame in my project plan was to allow up to 4 weeks to complete the first visual creation from the second visit, as well as allow up to a 3 month gap between the third and the fourth visit, to enable the child to have a break as I wanted to prevent any unnecessary burden. The reality of the time frames was not fully operational in the field

because of children's needs, family commitments, life events, CF sibling and parental health issues. Again this meant flexibility in accommodating family requirements and wishes. For some non-CF siblings it meant visiting the family earlier than the suggested four weeks and for some they required the longer gap between visits. Being realistic in the time scheduling was important, as David suggested I visit at 2am in the morning, but this was not feasible!

In pacing the visits it was also perceived necessary by the researcher to ask the participants to approach each visual topic in separate time frames to prevent any confusion for the child. This allowed them to reflect and concentrate on one topic at a time, to enable the generation of rich data that was relevant for this study. It was necessary to ask the participants to also do their visual creations whilst the researcher was not present so that I would not have an influence on their work.

This was an approach used by Mannay (2010) with her aim to make the familiar strange in a research setting that reflected her cultural milieu.

Mannay (2010) found this beneficial because it enabled a deviation from any preconceived ideas of the researcher as well as a structured interview. Hence, enabling a journey of discovery and new understandings rather than using a structured interview design. I had a conscious awareness that cultural familiarities may exist within my own research topic, in terms of family, siblings and chronic illness, due to my prior personal and professional knowledge and experience.

Fineman (1993) suggests that we cannot escape from the personal history that defines us. Watts (2009) discussed how working on her own autobiography within her research had confirmed this because connections were made where she came to understand herself. Therefore using participation inclusive of a visual elicitation, narrative and observation was aimed at helping to reduce my own preconceived notions to provide uniqueness, depth, and insight into sibling experience when

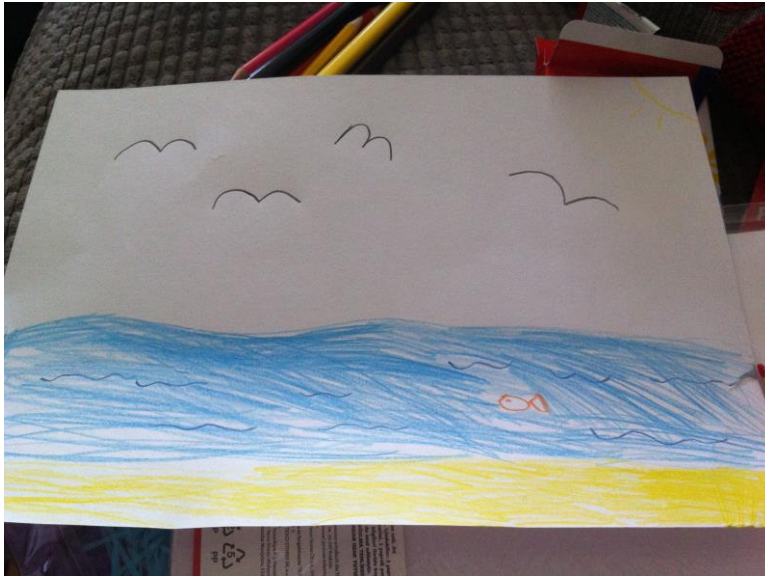
living with a brother and or sister with cystic fibrosis. It was aimed at determining the dynamic nature between self as a researcher and those being researched. Clarke and Hoggett (2009) suggest this is an important consideration in the choice of method for any research project.

3.8.2 THE SILENT SIBLING

A challenge that was experienced with one sibling (Raff) was that he chose to remain silent and to not speak for most of my visit. It was not that he could not speak, but he chose to not express himself with words. This was not helped by the fact that his sisters had informed him that I had come to take him away, because they had told him his parents were going to have him adopted and I had to reassure him that was not the case. His silence created a major challenge because despite this he clearly wanted to be part of the study and he wanted me to visit and to engage in silent activities. This meant as a researcher I had to be creative, flexible and adaptable and skilful in my communicative approach with this child.

Despite the challenge, he did engage in the making creative pictures and I was able to use strategies in which he could answer questions. These strategies included pointing to smiling/none smiling faces as well as asking him to point to certain things. We also engaged in card games and he skilfully was able to show me how he rode his scooter. Despite his silence, due to the methods used in this study, he was still able to be a very active participant in contributing to the work.

Raff presented the picture below, which was representative of a boat trip that he had been on with his dad. He did not like talking, but he enjoyed creating pictures.



3.8.3 PLANNING AN EXIT STRATEGY

A major consideration for this study was to ensure that an exit strategy was planned. I was conscious that I was building up a relationship with the siblings over several visits, which meant that they could become attached to me. In pre-empting this consideration, at the outset of the study I explained that I would only be seeing the siblings on four occasions and I reiterated this at each of my visits. However siblings/ parents were given my contact details if they needed to contact me for any reason throughout the duration of the study and after my final visit. Despite this pre-empted strategy, one child did become upset at my third visit when realization set in that the next visit would be my last. I re-iterated that she had my contact details and if she had further questions about the study then she or her mum/dad could contact me.

3.9 USEFULNESS OF THE STUDY APPROACH

3.9.1 SIBLINGS AS NARRATORS OF THEIR OWN CREATIONS

What was significant in relation to this participatory project was that the children became the narrators of their own creations, acts and performances, which enabled them to tell their stories to bring their worlds alive for the researcher. To remain cognisant with a participatory approach, the sibling creator told their story to provide their own interpretation of their work. This promoted sibling autonomy by enabling them to discuss their perception of their experience of their family life, as well as providing meaning to their encounter. This was important because there can be differing interpretative meanings viewed by the researcher and the creator which can influence the nature of the study (Kearney and Hyle 2004). It was essential to this study that the sibling voice is heard and that they give meaning to their experience.

Visual elicitation media and narrative as a method of participation in research has previously been used successfully to inform healthcare, policy, and education to enhance children's understanding (Schratz and Steiner Loffler 1998, Pink 2001, Radley and Taylor 2003, Leitch 2008 and Coad 2012, Coad 2015, Lomax 2015). It was viewed as very relevant for this study along with the use of observation. The table below represents the creative choices that children presented within this study in relation to the two topic areas of me and my family and future selves. Bakhtin (1981) and Bakhtin (1986) would refer to the children's choices as a persuasive aesthetic orchestration used to present the construction of self in a world where they belong.

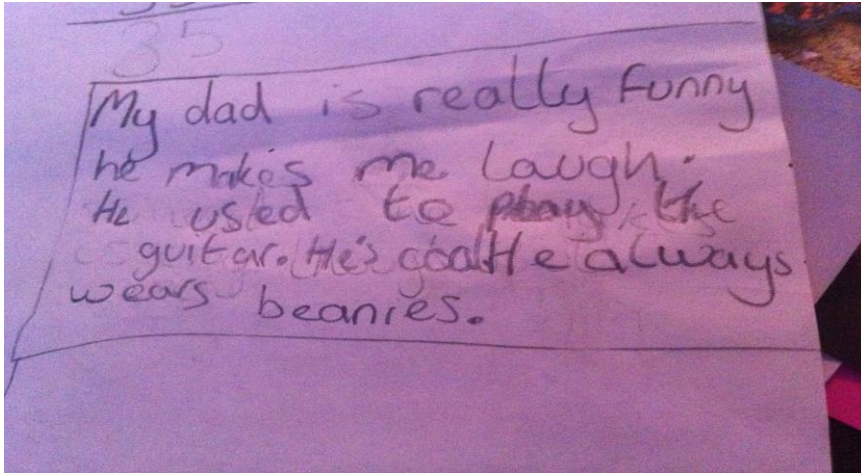
Table 6: Sibling presentation of their creative orchestral performance

Participant	Number of field observe Visits	Total time in the field	Childs choice 'Me and my family'	Childs choice 'Future Selves'	Childs choice 'getting to know you'	
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Josh	2	2 hours	0	0	Jigsaw	
Erin	4	4 hours	Collage/ Photograph	Photo/ Collage/	Singing Dance	
Charlotte	4	4 hours	Drawing/ Collage Photos Psalm	Talk	Game Play Play music	
Molly	4	4 hours	Drawing Photos Psalm	Talk	Game Play / gymnastics	
Raff	4	4 hours	Drawing/ Collage	Drawing	Scooter Game play	
David	3	3 hours	Drawing /collage	Talk	Loom band bracelet Making	
Elinor	4	5 hours	Collage Poem Family synopsis	Talk	Barbie/Action Man Play	
Hattie	4	4 hours	Drawing/ Collage Photos	Talk	Talk	
Nancy	4	4 hours	Drawing/ Collage Photos	Talk	Computer Game	
Adam	4	4 hours	Drawing	Talk	Computer Game	
Total	37 visits	37 hours				

Below is a brief synopsis that Elinor has written about her dad along with a picture of her collage:

The elements of collage are discussed in the findings chapters.



3.10 ANALYSING THE DATA.

Data generated from the bricolage of methods amounted to over 200,000 words that needed to be sorted and organised into manageable chunks to enable me to begin to make sense of it all. Mason (2002) suggests such categorisation to be an important first step in commencing data analysis. To prevent being overwhelmed by the data collated, I used Microsoft word to create a file for each sibling participant that was represented in their respective family groups. Field notes, narrative interview transcripts and pictures were then uploaded into their appropriate sections in accordance with their visitation codes. This meant easy access to each sibling script as well as the enablement of cross comparing of participant data through the tagging of data in the microsoft window frame whereby I could easily move back and fore between scripts. Due to my familiarity with the windows software and its ease of use, I chose to continue with using this package rather than using NVIVO or CAQDAS.

Goffman's (1959) dramaturgical framework of social interaction was used base my analysis. His framework is primarily focused on impression management as a consequence of performance given. According to Kivisto and Pittman (2007) Goffman's framework proposes key areas of analysis to include:

- 1) Roles / positioning
- 2) Scripts
- 3) Costumes
- 4) Stage and sets
- 5) Expression / Impression
- 6) Front stage / back stage

Kivisto and Pittman (2007) demonstrate their own analysis using these key concepts to explore their research of "personal sales and services in a commodified world". Their analysis demonstrates how this analytical framework can be applied to specific interactive social situations to gain a

greater understanding of the social reality of that world through the events that are performed in it. The approach has also successfully been used by other researchers, which also represent its applicability to a diverse range of socially interactive situations (Clarke 2014 and Ward 2013).

According to Reissman (2006) there are a multitude of approaches that can be used to analyse and interpret narrative texts with no single approach having exclusivity over another. Reissman (2002) highlights how the analysis of storied events can be political, textual, conversational or performatively conducted. Langellier (2001) suggests that in performatively analysing a story, it helps enable one's identity to be presented. Langellier and Peterson (2003) advocate for this approach to be used in order to gain detailed information within the context of a family group, so as to position the communication between the narrator, the characters and the audience to capture the doing of the story as well as the telling of it. Reissman (2002) places Goffman (1959) in the performative analysis category, which she views as an expansion of interactional approach, in terms of viewing the social action that is ensued in the coaxing, influencing and transitioning of an audience through an accomplished skilled performance that is moved beyond words alone.

Hogan (2004) highlights the importance of analysing narrative as a performance as he suggests the insufficiency of using content and structural analysis because it does not capture the positioning and interactive nature of the situated self. Hogan (2004) chooses a 'positioning analysis' approach to capture performance, but this would not have been suitable for this study, as my focus was not just on positioning alone. Following consideration of the literature above, and conducting a creative study of siblings within the context of their family whereby a multi method approach was being used to elicit narrative performance and stories, using Goffman's (1959) dramaturgic metaphor emerged as the most appropriate framework of analysis.

The analysis process itself was iterative due to the cyclical and repetitive stance taken in sifting through the data collected. Following organisation of the data and choosing a framework for the analysis, my immersion in the data commenced with my repeated listening to the audio transcripts alongside reading the written narratives. Where audio transcript was not used, only the field notes were repeatedly read. During this first phase of my analysis I was only half way through my data collection with 5 participants and did not have my full data quotient. During this preliminary stage it was my aim to become familiar with the transcripts and stories that were emerging. My focused immersion strategy in this early stage of reading was to capture the individual accounts of the participants. Therefore, I was getting to know the non-CF sibling to understand the context of their world. Reissman (2006) suggests the importance of recognising the sequential and consequential nature of the story and the meaning it portrays to its audience. I then made comparisons between each sibling/family group to look for common themes.

Initially I felt lost within the work and found it difficult to categorise and code the information due to idiosyncrasy, but what I did identify were moments of complexity and moments of chaos in the sibling worlds in relation to the cystic fibrosis disease trajectory. I highlighted and coded chunks of text in relation to key events such as when a cf sibling was admitted to hospital or had an intervention, as well as highlighting emotional responses of the non CF-sibling during our interactive dialogue in the transcripts. During this first phase I also began identifying the front stage performances in terms of early presentation of self, space, and visual images during my initial visits. In trying to make sense of it all I drew together some commonalities and wrote reams of draft notes in my attempt to capture themes.

An early theme that was identified was that of 'then and now' but in the preliminary stage I did not place it into Goffman's (1959) front stage or

back stage category and until further data were collected the theme lay dormant.

This preliminary immersion provided me not only with early insight into sibling worlds but also heightened my own awareness of my presence within the research environment.

As further data were collected from subsequent children I again read and re read the transcripts and listened to the tapes where available. I also used self-visualisation in reflecting back on and going over the visits in my mind to relive the scenarios and stories that I encountered with the children and their families. Along with the transcript and the voices I could place myself back to the situations not only hear the stories but to also see them and feel them again and again. Whilst this process weighed me down emotionally, drawing on the senses for the purpose of analysis was something I could not escape and it served to add to the analytical meaning, making journey. This resulted in further codes being generated through Goffman's (1959) dramaturgic lens. Extensive notes were generated from this holistic sensory approach. Sibling positioning of decentralisation within the family became more readily identifiable as well as my own position as a researcher who had subtly shifted a family dynamic in placing the non-CF sibling as central. I also highlighted recurring codes across all the sibling family groups in relation to sibling roles, sibling places as well as wellbeing and emotional status. At times I felt I was breaking things down too much, so I pieced the segments back together to enable me to really look at the stories to see what each one was trying to say. Like a jigsaw I was deconstructing and reconstructing the stories and performances so as to provide researcher interpretation.

Each stage of the process in terms of individual cases, identified codes and extensive notes were discussed with my supervisors. I also attended a master class on narrative analysis and interpretation that was facilitated by Gerhard Reimann who is an expert in the narrative field. The

experience enabled me to not only engage with other students in terms of analysing other pieces of work, but also enabled me to consider ‘what is each story trying to tell me’? Following the workshop, further supervision and rereading each story with all codes and notes removed, I finally saw the play with the actors, the stories, the front stage, back stage and contradictory performances. In the iterative process I had finally come full circle. During supervision with both of my supervisors I was able to begin to talk out and bring the key acts together to formulate a framed dramaturgic theatrical production.

Table 7 Outlines the summary of the process of data analysis that I engaged in, which has been adapted from Wolcott (1994) who suggests a 3-stage process for analysing qualitative data to include description, analysis and interpretation. My adapted version also incorporates an organisational phase and refers to the descriptive phase as preliminary, in relation to my own process of analysis encountered.

Table 7

Process of data analysis and interpretation – adapted from Wolcott (1994)
<p>Organisational phase</p> <p>Create file for each sibling/ family group using Microsoft word</p> <p>Section each file in chronological visitation order</p> <p>Place pictures and artefacts in relevant sibling file</p> <p>Upload audio tape to sonic software programme</p> <p>Choose analytical framework: Goffman (1959)</p>
<p>Preliminary Phase (Iterative)</p> <p>Read each narrative/performance at the moment of transcription</p> <p>Listen to each tape</p> <p>Reread and listen to transcripts with completion of 5 participants</p> <p>Supervision discussion.</p> <p>Early identification of codes ‘complex’ ‘chaos’ ‘front stage’ moments in the application of Goffman’s (1959) framework.</p>
<p>Analysis Phase (Iterative)</p>

Read, reread, listen and visualise transcripts pertaining to narratives and performances.

Supervision discussion.

Attend master class workshop.

Identified themes collated in relation to; front stage, back stage, role, positioning and contradictory performances identified and described.

Data generation complete.

Interpretation

Three Key Acts identified with thematic/individual scenes outlined to formulate a drama production and a discussion

3.11 ETHICAL CONSIDERATIONS AND MINIMISING RISK

Respecting the rights of the participants throughout this study was paramount to uphold the principles of research governance and ethics. The study followed the appropriate ethical guidelines throughout the research process. Guidance included the Research Governance Framework of the Welsh Assembly Government (2009), Cardiff University Research Governance for Health and Social Care in Wales (2009) and Cardiff University Research Governance (2010). Furthermore the Royal College of Nursing (2009) Research Ethics: RCN Guidance for Nurses and the UK Research Integrity Office (2009) Code of Practice for Researchers will also be considered. As a nurse researcher I was also registered with the Nursing and Midwifery Council therefore adhered to the NMC code of conduct (2008/2015). Ethical guidance and scientific review was also sought from the Research Review and Ethics Screening Committee at the School of Nursing and Midwifery Studies, Cardiff University and The Florence Nightingale Foundation. Approval was also gained from the North Wales Research Ethics Committee and two local health boards, although only one needed to be used due to completion of recruitment.

To minimise risk in the study, the researcher did not contact participants recruited from clinics directly. The consultant paediatrician or children's respiratory nurses spoke to families first to inform them of the research study to see if they are interested in taking part. I only met participants once they expressed an interest to know more about the study and as the chief investigator I was then able to discuss the study and gain their consent to enroll in the study.

Gaining consent was an essential part of the research process because the vulnerability of children must be acknowledged according to Matutina (2009). Siblings, their family and significant others received information sheets and verbal information explaining the purpose, process and duration of the study. They were informed that confidentiality would be maintained and they could choose to withdraw from the study at any time if they had wished to do so. Twycross et al. (2008) and Shaw et al. (2011) provide a guide for nurse researchers to ensure that children and their families understand what is involved in the research study, so that an informed choice can be made regarding participation. A consent form was provided with consent gained from the parents and consent/assent also obtained from the siblings prior to inclusion in the study. If the parent had provided consent, but the child did not, then the child's decision would have superseded that of the parent. However this was not an issue in this project.

Health and safety guidelines were followed when visiting, interviewing and conducting observations at the siblings home. Guidelines included those from the university, the relevant health boards and the Health and Safety Executive (2009). The safety of the participants and the researcher were maintained throughout this project. I adhered to the Cardiff University (2009) fieldwork policy by undertaking risk assessment to identify potential hazards and to minimise any risk to self or participant when visiting participants. I met regularly with my supervisors to maintain ongoing

communication about the project and raise any safety issues for discussion.

Children were able to negotiate time scales and activities throughout the work, so as to prevent them becoming burdened or pressured in any way. They were also informed that they only needed to talk about things they were comfortable talking about, as they would guide their narrative and with myself as a researcher only offering prompts were necessary. They were not asked intrusive questions or pressured to provide answers that they did not want to give. If a sibling were to become upset at any time then they were informed that they could stop talking and that they could withdraw from the study at any time. It was also important to ensure that a parent was at home and within close range in case a child did become upset for any reason. As a researcher I was able to manage situations of a delicate nature when talking and listening to the children due to my experience as a children's nurse.

Participants were informed of the purpose of the study and the intention to disseminate and publish findings. It was anticipated that quotations would be published when the study is reported in journal articles and conference papers, to give weight to the findings of the study. I have acted in accordance with the NMC code of conduct (2008; 2015) during field visits with participants. Siblings and their families were informed that where any of their quotations are used when publishing/disseminating findings, that the quotations will not be attributed to a set person. They were informed that pseudonyms will be used at all times and will not be traceable to individual participants.

On completion of each of the data collection phases and narrative interviews, the child and family were informed that they could contact the researcher if they had any further questions about the project. They were also informed that the researcher would provide a summary of the research information at the end of the study. Having a point of contact was

seen as necessary because the child may find it difficult if they could not have some form of contact with the researcher following being involved in the study. During the study and on completion of the data collection the child will still be able to contact the researcher if they have any questions or concerns, so that they do not feel abandoned by the researcher. My contact details were provided on participant and parent information sheets.

3.12 CONCLUSION

Preparing for a dramaturgical production is not an easy task, as it requires time, commitment, motivation and determination in order to provide the right scaffolding for a play to take place. Actors and audiences need to be prepared for their participatory roles, which can be enhanced through the use of the appropriate resources as well as the provision of safe spaces and places allowing them to perform, give voice and tell their story. This chapter has discussed the behind the scenes journey where epistemological, methodological (narrative inquiry), ontological (children as social actors/interacting) and dramaturgical insights to the study have been highlighted. A bricolage of methods has been presented and safely used following ethical approval, to enable children to be active participants in the research process. Using creativity is synonymous with the phenomenon of the 'being child'. This approach has encouraged non-CF siblings to have a freedom to express themselves in a multitude of ways in accordance with their own cognitive ability and preference in the cultural context of their family world. Their persuasive impressionistic, metaphorical, creative storied performances have generated data for analysis and interpretation using Goffman's (1959) framework, which have enabled three staged acts to be presented within the next few chapters. The staged acts are presented as a production called "Segments of the sibling mosaic".

A Three-Act Play
“Segments of the sibling mosaic”



4. CHAPTER FOUR: PROLOGUE

Normally one would expect to see a prologue at the beginning of the thesis as opposed to prior to the three findings chapters. However this prologue is situated here to provide reflexivity and transparency along with the emerging awareness of the researcher whilst conducting this research.

The two scenes below have been chosen to represent where blurred lines have become clearer in the moments of a life forgotten, but one which was experienced by myself as a child, a life placed in the unconscious carefully locked away then only to re - emerge back into conscious awareness with a vengeance as a result of my research journey when visiting siblings in their homes. Whereby vivid images, strong evoked thoughts and feelings from the scenes led to nocturnal awakenings due to the hype of activity going on in my head that I was trying to make sense of. Such activity informing me that the time has come, the time is right to move the hidden into the aware to create cognizance that will reframe and reformulate my existential being. The person I was, the one I forgot, but now must accept, the person I have become in life's transition, the person I am in conducting this research and the hope of who I will become in the future.

The two scenes are symbolic of where the child of yesteryear meets the novice researcher of today. When they merge into one with the realization of how the past experience of the little girl watching has influenced the researcher in the making in writing this work, a researcher concerned with creativity and using the senses, a researcher concerned about siblings in their families where there is a chronic illness. One, who has resonance, is sensitive, has empathic knowing and readily engages with the families that she meets. They represent a moment of coming to know, becoming whole, knowing and understanding one self.

Without really acknowledging the past there can be no understanding of the present that can continue to influence the future.

4.1 SCENE PROLOGUE: A LITTLE GIRL SITS WATCHING Circa 1973

The little girl was sat up in the cream wrought iron railing bed. She had shoulder length dark hair, dark eyes, and pale skin and was slightly emaciated with a large distended tummy. "We are too scared to touch her in case she might break" she would hear them say. The little girl was not very well. She was propped up with four pillows that were placed and plumped up in the shaped of an armchair around her. The bed was dressed with starched white linen with a pink top sheet that was embossed with white teddy bears. This was the little girls' favourite out of a choice of a blue, green or white. The bedding was all neatly tucked in to perfection, so much so the little girl was tightly enclosed, but she was comfy in her makeshift armchair because she could see what was going on. To either side of the bed were curtains with lots of characters on them, rabbits and frogs like the characters out of the Beatrix potter books. Across the bed was a white bed table with cream wrought iron legs. The table was where she could place the things she needed to hand. Today all that was there was a plastic water filled jug with an orange lid placed on top and a plastic glass to the side half filled with water. She did not have anything else; she did not need anything because she was happy to just be sat up just watching what was going on, as she could not get out of bed. Sat with her was Patsie Panda her favourite teddy, Patsie Panda was watching too. There was a lot going on. So as she cuddled up with Patsie she just observed the show.

The little girl's bed was opposite a glass front office with a blue door and painted surround. Historically in that era it was known as the sister's office on a busy children's ward in a children's hospital (In contemporary practice it would be the ward managers office). She knew she must be ill if she was opposite the glass office because that was the place they put you if

you needed to be watched closely. The office was sometimes a hive of activity with the doctors in white coats coming in and out and the nurses having their hand over meetings in there. The staff nurses wore grey uniforms with white starched aprons with red belts with silver buckles and frilly white hats and frilly arm cuffs. Their hair was neatly pulled back off their faces and enclosed in a knitted bun net. The nurses in green with dark green belts, and starched white aprons were enrolled nurses. The ward sisters wore blue and also had frilly white hats worn slightly higher than the staff nurses, there were two of them in charge of the ward, one had blonde hair and one dark. The little girl noticed that they did not seem to get on with each other. The auxillary nurses wore black and white pinstripe dresses.

It was in the glass office where they decided who would look after who that day. The little girl wondered who would be looking after her. She could often see people talking in the office, she got used to watching so much that she learnt to lip read. She always was able to tune in to what was going on, whether it was a good day or a bad day, if there was a poorly child or bad news to be broken. No one told her, but the little girl knew, she sensed it, she felt it. Sometimes other parents would ask her "what's going on today?" She picked up on the cues, the nonverbal indicators, the ward atmosphere, the way people walked and the looks on their faces. She sensed their aura.

Sometimes she would play a game to imitate the different facial expressions as a way of occupying herself as she was sat on her own. While she sat waiting to find out who was her nurse and sat waiting for her mum who would visit from 11:00 hours until 14:00 hours and then 17:00 hours until 19:00 hours everyday. Those were the times she had a visitor.

The ward was a long Nightingale type; there were cubicles with tiny babies either side of the ward to the right of her and to the left lots of beds and cots. There was a playroom half way up the ward on the right hand side

and opposite that was a room she did not like, that was the treatment room with the big blue door. She always cried when she was taken in there, there was another treatment room to the top end of the ward (She hated that too) and opposite was a bathroom. At the very top of the ward were glass panelled patio doors that did not open but they overlooked the nurses living quarters where sometimes they had parties. She could see people coming and going and hear their music playing. That was an aspect of the outside world she could see from her bed. The other windows on the ward were too high to see out of.

It was a long ward and very busy. She knew the routine, as it was not her first time here, she had been here lots of times. The lights would go on at 5:30 am and the bed baths would start. The night nurses would start at one end of the ward with the back trolley and then work their way up, making sure the children were washed, had fresh clothes and that the beds were made. Then it was breakfast time. The little girl would have tea out of a baby beaker, white buttered toast and rice crispies, if she was allowed to eat that was. By the time it was the shift change all of the children were up, fed, washed and ready for the day staff, ready for the ward round with the doctors in white coats. When the doctors came round, it was deadly silent. Everyone had to be on their bed, whether they were going to be seen or not by the consultant. The last person to be seen had to sit on their bed in silence and wait until it was their turn. There was a big silence on the ward, so much so you could hear a pin drop.

When the little girls mum was there the little girl would ask "Why does everyone have to be quiet mummy?" and her mum would just say "Shhh". The little girl had wanted to speak but instead she had to stay quiet and just watched the doctors go from bed to bed around the ward. She heard their quiet whispers as they talked to parents and children. Sometimes she heard the parents cry when the doctor spoke. She knew that was not a good sign. She remembers two little girls of the same age having the same condition. They were both very yellow looking when the little girl saw

them. For one it was good news she was going to get better, but for the other it was not. Something went wrong and the doctor mixed the children up and told the wrong parents that their child was not going to survive. There was an atmosphere on the ward that day because the most awful thing had happened and the doctor had to rectify the mistake.

When the ward round was over the silence broke and the little girl could hear babies crying and other children playing. The play nurse wearing yellow with bright red hair and her big beaming smile would come around and ask if the children wanted to play. The schoolteacher would come around and ask the little girl if she felt up to doing any schoolwork that day. The teacher was not too bothered if the girl did not do the work because she was not well and had not been in school long, but he left something just in case. There were two schoolteachers, a man called Mr Gandal and a woman whose name she did not know. The female teacher was very tall and slim with curly blond hair. She would walk with a big stride and her feet turned out. The walk fascinated the little girl and when she was able to get out of bed she imitated the walk, luckily not for long.

Now the ward round was over she could hear constant noise of music playing from the cot mobiles and play tune toys. The little girl would often sing to the tune from the toys:

“Row row row the boat gently down the stream,
Merrily, merrily, merrily, merrily,
Life is but a dream”.

But this was no dream, it was real, the little girl was in hospital for 3 months. It was a time of waiting:

She waited for the day to begin and the day to end.

She waited to find out who her nurses were on each shift.

She would wait for her favourite auxillary nurses to come and talk to her at 7 pm when it was time to have the locker washed and the paper rubbish bag removed.

She would wait for her two favourite night nurses that would lift her out of bed to sit her on their knee while they were chatting and knitting after doing their evening back round/medicine round duties. They would give her a cup of Milo out of a baby beaker as a bedtime treat before putting her back to bed so she could sleep.

She waited nervously for the doctors to come and the doctors to go as they evoked moments of fear, especially if her mum was not there. Sometimes she would ask "Please will you wait til my mum comes?" and then they would wait to the little girl's relief as she held on tight to Patsie panda.

She waited for the moment when she could leave the ward and just have a walk along the hospital corridor so she could sit on the giant horses. Sometimes when she was able to get out of bed she would sneak off the ward and wander around the hospital corridor and meander in and out of different wards and departments to see what was going on.

She waited for a breath of fresh air and just to go outside.

She waited to see her friends again.

She waited for the teacher, for the nursery nurse, and for her mum. Just for moments of attention.

She was waiting for the future because she wanted to become a children's nurse.

Sometimes she felt lost and sometimes experienced moments of helplessness, but then she had an inner strength and determination that meant she would never give up that hope of going home.

While she waited she just watched and took everything in.

In this time of waiting, she watched, she felt, she listened, she heard, she smelt the clinical smell of the ward environment, and she continually tuned into her senses while she waited for so many things:

But most of all she waited for her time to be moved up to the top end of the ward, she knew if you moved up, you were nearer to a time when you could go home. She was waiting to just go home. Little did the child know that her attuned senses from all of the waiting and watching would be useful in her future life. Her waiting would be worthwhile.

4.2 SCENE P2. THE SIBLING IS HIDING

3 months later

The little girl carries Patsie Panda as she arrives home from hospital with her mum; Her tummy is no longer swollen and she has put weight on and she looks much better. She walks through the front door into the hall and then to the left through the door and into the lounge. Everything feels strange because the little girl has not been here for a while. She takes a moment to just look around and familiarise herself with her surroundings and just being home. To the left is an embossed dark green armchair and next to the chair is a chunky looking television on four legs that you would almost expect to see on a chair rather than the television. The gas fire was central to room but it was not lit, not like it had been before the girl went into the hospital. The seasons had changed and the fire did not need to be on. There was a large settee against the wall and a white plastic round coffee table to the left with a small lamp resting on it. The walls were painted cream with wood chipped wallpaper and the carpet a brown patterned colour. The green telephone was in its place on the coffee table and the large brown radiogram/stereo system was to the right of the room.

The little girl was looking for someone when she got home. She was looking with wide eyes for her sister. "Where's my sister?" She asked. All was quiet. Her dad spoke "come out from behind there". Then a girl appeared from behind the settee that was up against the wall, (she had

been crouched down and squashed hiding in a small space at the back of the settee) but this girl was taller and older than the little girl. She had not seen her for 3 months. She had grown. She was slim with clear but dry skin (she had suffered with nervous eczema), she had big blue eyes, long brown hair scraped uncomfortably back off her face as her mum would always pull her ponytail too tight, the little girl recognised the discomfort in her sister. As the older sister appeared from behind the settee the little girl asked, "What are you doing behind there? Why are you hiding?"

The older sister looked coy, shy and spoke quietly as she replied, "I am playing with your dolls, and I hope you don't mind." She looked nervous as if she had done something wrong.

The little girl replied, "That's okay, you did not need to hide"

The big sister looked relieved as if the little sister would scorn her.

The little girl smiled but remained puzzled as she wondered why her sister had been hiding? Why her sister was not waiting for her to come home? And why had she not visited her at the hospital? The little girl had missed her sibling but these moments of confusion faded as there was a lot of activity that surrounded her as her welcome home party was about to begin... the little girl was happy that she was home because now she was with her sister.... until the next time.

4.3 THE INVITATION AND THE INANIMATE GUEST

Presenting the two scenes above laid my intrusive nocturnal images to rest and allowed me some restful sleep as I recognised their significance with their burning desire to be written on paper. As the words flowed my mind was freed, my blocks became unblocked and I became ready to invite you into this dramaturgic production.

The curtains of this "three act play" will soon be opening, so please take a seat as I lead you through an experiential journey of siblings that are living

with a brother and/or sister with CF. But before we start there is a guest to invite as an important observer to represent elements of a lost childhood/historical journey of the researcher. The inanimate guest observer is invited to watch as the sibling worlds unfold within their families. My inanimate panda has re emerged since commencing this research. A panda that is still very much intact despite being hidden away in a cupboard for many years. The panda is now on display in a significant place in my home. It is a panda that was carried around on a childhood journey, with eyes intact it has seen a lot and offered much comfort.

In recognition of the symbolism of this teddy bear for “The little girl in waiting” and the scene of “The sibling is hiding”, Patsie Panda will take pride of place in a fictitious seat alongside the reader and will be present as a mark of respect for childhood and of the experiences of the children and families in this study. As the dramaturge commences I ask you to understand the importance of its presence, as no child should feel alone in there journey. There were particular moments in this research where I thought some of the children would benefit from the comfort of such a panda.

“Every adventure requires a first step”

The Cheshire cat
Alice in Wonderland
Lewis Carroll

5. CHAPTER FIVE: THE EXPOSITION

SETTING THE SCENE AND PRESENTING THE STAGE SETS

5.1 INTRODUCTION.

This chapter will present the characters of the three-act play that is called 'segments of the sibling mosaic'. The play has been formulated to present the findings of this research with its portrayal of the parallel lives of children that are living in a family where they have a brother and/or sister who have a diagnosis of CF. Within the next three chapters, three 'theatrical acts' will be presented and are entitled "The decentralized sibling", "The importance of being good" and "Authentic selves". It is here that Goffman's (1959) dramaturgic 'lens' has been used to provide an in depth exploration of sibling front stage, back stage and centre stage narrative performances. Siblings are presented in their own home stage set and in the context of their individual family life. Within each act specific scenes are highlighted to enable the exploration of the non-CF sibling narratives, performances, observations and visual representations, as well as their dialogic interaction within the context of their family. The scenes will demonstrate the multi faceted nature of the sibling experience and how this influences their presentation of self and their co constructed lives.

I have intentionally adopted a narrative, descriptive approach in presenting the findings as opposed to using usual verbatim quotes, to enable every child that was a participant in this study to have their own voiced performance heard. I felt I had a moral obligation to do this because in asking children to be involved in the study, I had promised that their voices and performances would be presented. I was conscious that I did not want to leave any child out despite the large amount of data I had collected. I felt it would have been an injustice to the siblings if I had only focused on a few cases to represent their stories. The most significant elements of their experiences are presented which are relevant in this research study

Throughout the findings chapters my own stage presence as the dramaturge who is the key narrator and director of this production will be visible as I interweave and metamorphose into several roles including a researcher, key player, actor, spectator, reflector and writer. Some elements of reflection are presented in scenes of fantasia within the chapters.

The characters in this dramaturgical production are based on real people; places and experiences and are temporal to the moment of my research visit. To protect the identity of the siblings and their families each character has been provided with a pseudonym. Any place names mentioned will also be a made up name.

Prior to introducing the characters I will provide an overview of the terminology that will be used when referring to selected roles within this production.

5.2 NON-CF SIBLINGS AS PROTAGONISTS

The non-CF siblings within this study are referred to as protagonists because they are the key characters of focus for this work and are central to this research and my focus for this thesis.

5.3 CF SIBLINGS AS ANTAGONISTS

Brothers and sisters with a diagnosis of cystic fibrosis are referred to as the antagonist regardless of whether their relationship with their sibling is positive, negative or ambivalent. Using the term antagonist is not meant to label CF siblings in a negative sense but merely to provide a dramaturgic view of the character along with experiential context that has been highlighted within non-CF sibling narratives and performances.

5.4 THEATRICAL STAGE SETS

Key family places and spaces that are visited within the sibling's home will be referred to as stage sets. The stage sets will describe and discussed where relevant to the context of specific situations.

5.5 KEY PLAYERS

Parents and other family members will be considered as key players rather than antagonist as they are viewed differently than the antagonist and protagonist through the dramaturgic 'lens' as they are the main carers in the child's world.

5.6 THE RESEARCHER AS: THE DRAMATURGE

As the dramaturge for this study I have drawn on my professional milieu to select and formulate appropriate scripts to present the characters and to tell the sibling's story based on the analysis and interpretation of their narratives as well as their performances throughout our research journey i.e. the joint journey of the non-CF sibling and myself. It was important to ensure the sibling voice was not lost and using a participatory approach has enabled siblings to guide the work.

5.7 PRESENTING THE PROTAGONISTS

The protagonist siblings will be introduced in the context of their family and a brief synopsis is offered in relation to their worlds. To have a greater understanding into the experience of the protagonist it is essential that they are not viewed in isolation because their family is the mainstay of their life. Each child is introduced below with either one or two of their siblings with CF.

5.8 CYSTIC FIBROSIS AS AN OPPOSING FORCE

The play will present CF to be an opposing force within family life because the narratives have exposed that living in context of the disease can present challenges for the protagonist. Having a sibling with CF that is acting as an opposing force (antagonist) to the protagonist in terms of these experiences will be discussed in the acts, scenes and stage sets within this play.

5.8.1 AN OVERVIEW OF THE PRESENCE OF CYSTIC FIBROSIS IN THE DAILY LIVES OF FAMILIES IN THIS STUDY:

An overview of the presence of CF in family life is presented here to provide further background insight prior presenting the findings. Examples

and excerpts from field visits are provided as evidence here purely to highlight some of the issues mentioned.

CF is a genetic lifelong, life limiting disease as was established in the exploration of the literature in the introductory chapters of this work. I have observed through my field visits and did have some prior knowledge as a respiratory nurse that it is a disease that is multi faceted in nature as it is a multi system disorder that affects the lungs, the gastrointestinal tract, endocrine and reproductive systems. Management of the disease for families visited in my study includes their daily routines of physiotherapy and the active cycle of breathing. Maintenance of the disease also includes children with CF taking daily nutritional supplements, vitamins and gastric enzymes (Creon) with every meal at home and at school. To demonstrate the nutritional requirements, below is an excerpt from my field notes, which is taken from a phone call I received from a mother who wanted to talk to me about her experience of her child/siblings experience of CF.

*“You want to hide CF but you can’t hide it from the sibling”
Grace provided an example in terms of mealtimes and eating*

She discussed how Skye requires 1,000 extra calories per day because of the CF and she also needs Creon added to her food. She requires extra fat in her diet.

Grace discussed how they need to encourage Skye to eat and will give her desserts and high calories drinks and then Belle her non cf sibling will question that and she will say “why can’t I have a dessert?”

(Grace: Mother of two siblings, one with CF and one without, April 2014)

Children also need to take nebulisers every day (some of which were bulky, noisy and time consuming) or inhalers as an addition to their management.

Hattie a non-CF sibling shows me the nebuliser that one of her sister’s use in the next picture.



Some of the CF siblings that lived with the protagonists in this study also took daily laxatives to help them go to the toilet and this was either via self-administered daily enemas (supervised by their mum) which resulted in the CF child having a total bowel clear out before they went to school or by way of oral medication that meant the child would spend 20 minutes or so on the toilet when they came home from school.

During one of my field visits to the cystic fibrosis clinic one of the mothers spoke of the priority of her child's cystic fibrosis treatments:

“Billy (child with CF) does take priority at home because of all his treatments and his condition. Sometimes I have to just leave all the others on the settee and get on with him (referring to Billy). She said that the siblings “do get left” because “his treatments take up so much time”. (Mother in CF clinic, field visit, February 2014)

Hospital appointments for CF children would vary between being monthly/or every other month and they also have to attend for an annual follow up appointment at a local hospital and at the main children's hospital/cystic fibrosis centre.

Visiting the main CF centre did add to family time and financial expense, as they needed to travel a longer distance to get to the clinic. It can be the difference of being out for a whole day instead of an hour or two for the families.

The main aim of treatment and management within these families was to keep their CF child's lung function as good as possible and to prevent any infections being colonized in the child's lungs. One of the most dreaded infections that families wanted to avoid was that of *Pseudomonas aeruginosa*. This is a difficult infection to treat and once it is colonized it is difficult to get rid of. A couple of families mentioned that their child had *Pseudomonas* that was treated when their child was much younger and then the *Pseudomonas* had remained dormant only to return whilst I was conducting my visits.

Another aspect of ensuring good infection control was parents and children are not able to socialize with other families with CF. Any clinic visit has to be carefully scheduled to make sure that none of the families had contact with each other for fear of cross infection. There was a sense of isolation for the families in terms of being in touch with other families who had a child with CF and there was a large reliance on social media technology with some families being part of closed groups that could not be accessed by healthcare professionals. When colonized lung infections did occur this meant that mainly mothers spent two weeks in hospital with their child whilst they had intravenous antibiotics and for some they would have the intravenous antibiotics at home. For families with two children with CF it could mean double the hospital stays for two weeks.

All of the CF children had portacaths fitted in their chest area to allow the taking of blood and the administration of the intravenous antibiotics. Care needed to be taken in looking after the portacaths in case they also become a site of infection or cease to work if they are not cared for properly and become blocked. A portacath requires a maintenance flush at regular intervals to maintain their patency. The portacaths were visible to their non-CF siblings when children undressed or attempted to bath together.

CF is a complex disease with many genotypes and there are many predictable/non-predictable complications that can occur along the trajectory. Interestingly all of the parents knew the genotype of their child. I was informed by a consultant paediatrician on one of my clinic field visits that for a parent to not know their child's genotype was seen as bad parenting within the CF community i.e. from other CF parents not the healthcare professionals. The child's genotype can be a predictor for the care and treatment given as well as the presentation and severity of the disease itself.

The CF siblings living with the protagonists in this study were all living within the cystic fibrosis trajectory. Each individual was at a different trajectory point in relation to the disease and their journey during my visits. Some of these trajectory time points will be mentioned in relation to the non-CF sibling experience to exemplify normal, chaotic and complex moments within their lives.

5.9 ENTER THE PROTAGONISTS LIVING IN PARALLEL WORLDS:

An important element of this exposition is to present and explore the main actors of this play so as to enable their stage presence. In total there are 10 protagonists and each one will be presented individually within the context of their family life with family members and their key stage sets. Commonalities between the protagonists that have been identified from the data analysis will also be discussed. All of the young people in this study are white Caucasian because cystic fibrosis is predominant in this population as opposed to other ethnicities. Eight of the children were visited on 4 occasions during this study. One child David was visited on three occasions but all of the information required for the research in terms of the 'me and my family' and 'future self' theme was obtained during this time period. Three visits were only possible because there was a breakdown with a family relationship, which meant a fourth visit, was not appropriate in view of the family circumstances. Josh was only visited on

2 occasions because his mum cancelled my third visit and then I was unable to gain access.

In presenting the characters I am presenting an overview of the children's personas/roles. Some of the descriptions in their characters will be discussed in more detail within the three chapters where they link to key themes for discussion. However I have mentioned them here to purely set the scene.

5.10(1). PROTAGONIST 1 - JOSH

Josh is a 9-year-old boy with very short brown coarse looking hair with pale skin and freckles on his face. He is of an average height for his age, he looks healthy. Josh was wearing his school uniform of a red sweatshirt jumper and a pair of grey trousers when I first met him. He is quietly spoken and mainly looked straight ahead while we were talking rather than giving any eye contact particularly on my first visit. Josh likes playing football. He is quiet and shy but has a very responsible and caring manner. He is the eldest child in his family.

5.10.1 FAMILY MEMBERS:

Key players: Josh's mum Jenna and fiancé soon to be husband (mum is no longer with Josh's dad)

Antagonist: Billy age 5 (Billy sits having a nebuliser in the lounge during my first visit, I had met Billy before at the cystic fibrosis clinic. He wanted to talk to me but could not because he was having his treatment). Billy is small, very pale and thin. He has brown hair and his mum is concerned about his behavioural issues.

Other siblings Jake age 7 and Layla age 2.

Pet dog: Bobby

5.10.2 GEOGRAPHICAL LOCATION

Josh lives in a built up area not far from a busy motorway in a house above a precinct/small local shopping-centre in an enclosed formatted square, so the houses are terraced, two story and are overlooking the shops. Effectively the houses were built on top of the shops. There is no

garden but a small walkway leading to each house surrounded by wrought iron white railings.

5.10.3 HOME STAGE SET.

To get to the stage setting in Josh's home I entered a small hallway with a door to the left of which was a small kitchen where part of one of my visits took place. There was then a closed stairway to the left before entering the lounge area. It was a large room that looked newly decorated and had a modern feel. There was a black leather settee along one wall and another one along the other. The floor was wooden laminate. There was a shelf just to the left of the door and I could not help noticing that there was equipment that was for Billy's CF treatment on this shelf, it was fairly high up and would only be reachable by an adult or much older child. There was a large television to the right hand corner of the room and it was playing during my visit. Jenna was sat on the settee playing with her phone and Billy was having his treatment. Initially Josh was off stage, he was out of the way and Jenna shouted for him to come down the stairs. I took my seat on the settee by the far end wall and waited for Josh's entrance.

5.11(2) PROTAGONIST 2 - MOLLY

Molly is a seven-year-old girl, (She was just coming up to her eighth birthday at our first meeting). She is of slim build and of average height for her age. She has mousy brown shoulder length hair. She has big eyes and a big smile. She is wearing her school uniform of a blue blouse and a grey skirt. My first impression was that Molly was vibrant, inquisitive, smiling and very excitable. This impression continued throughout my visits. She had a primary concern for her sister the antagonist and was very much the playmate, the pleaser and at times a peacekeeper. She also looks up to her older sister Charlotte. Molly is the middle child within the family.

5.12(3) PROTAGONIST 3 - CHARLOTTE

Charlotte is 11 years old she has mousy brown hair that was tied back from her face; she was also of a slim build like Molly. She was wearing her school uniform of a pale blue blouse under a grey jumper and a grey skirt. During my first meeting with Charlotte I noticed that she would listen and observe what was going on and ask some relevant questions about the study and she would occasionally interject if she thought Molly was becoming too excitable. On the whole she was sensible, reserved, polite and thoughtful. Sometimes she would take on a parenting role with her siblings. Charlotte was the eldest of the three children. She was in a transition phase of preparing for her move to secondary school.

5.12.1 FAMILY MEMBERS

Molly and Charlotte live in the same family.

Key players: Mum, Amanda and dad, Dave. Amanda works in the children's school part time. Dad also works but I was not made aware of his job.

The antagonist: Emma age 3. Emma is very slight in terms of her build, she is pale skinned and has blond curly hair. She is fragile, chatty and friendly. She becomes extremely distressed when undergoing any intravenous treatment or when having blood taken. She has recently been diagnosed with pseudomonas aerogenosa.

The family have a pet dog.

5.12.2 GEOGRAPHICAL LOCATION

The visit took place in the family home, which is a relatively new build detached house on a small estate. It was within easier commuter distance to the motorway and not far from a local main supermarket. The house was situated in a quiet close just off the wider estate with houses either side and a large red brick wall was opposite the house. The surrounding houses were all of similar design but of different sizes and were all detached.

5.12.3 HOME STAGE SET

From the outside of the stage set I could see there was an open plan small grass verge garden at the front of the house. The house had a porch way to the right hand side of the build with a painted shiny dark blue door. The porch way led straight into the lounge area. It was a modern design inside and had an open plan lounge dining area that is separated by the specific setting of the furniture and there are patio windows overlooking the back garden. Off to the right of the dining area there was a door to the kitchen and a separate door leading into a hallway with a downstairs bathroom and the stairs. The place is a contemporary setting, very light, bright and airy with a wooden floor and 2 leather settees. Behind one sofa is a dining table surrounded by dining chairs. This then overlooks a sizeable garden that contains a trampoline for the children. For all of my visits I sat on the sofa that faces the fireplace and is nearer the front door. The other settee provides a dividing line between the dining room and the lounge area.

5.13(4). PROTAGONIST 4 - RAFF

Raff is an 8-year-old little boy with blonde curly hair. He is very slim and pale looking. He looks withdrawn and appears sad at our first meeting. He is extremely shy, quiet and apprehensive as he held his head down toward the floor quite often and exhibits an almost inferior status. He refrains from eye contact most of the time and he does not speak. It is not that he cannot speak; he just chooses to nod or shake his head rather than talk. He also responds and interacts through pointing, drawing and playing games. Raff on the whole had a passive nature. Occasionally he will speak very quietly. He likes to draw, ride his scooter and he likes playing with his pet dog. Raff wears a school uniform of a yellow polo shirt and grey trousers. Raff is the youngest child in his family.

Within my field notes I chose the words of an Abba song in one of my reflections to capture the essence of Raff's character. Hearing this song on the radio on my way home struck a resonance with me in terms of what I had just experienced. My first visit with Raff left me feeling burdened and it was a significant moment in my research journey.

*“Chiquita, tell me what's wrong
you're enchained by your own sorrow
in your eyes there is no hope for tomorrow*

*How I hate to see you like this
There is no way you can deny it
I can see that you're oh so sad, so quiet”*

Chiquita (Lyrics by Abba)

5.13.1 FAMILY MEMBERS

Key players: Mum and Dad. Mum works part time and dad works full time

Antagonist 1: Bonnie age 10 years old was a well looking girl of average build for her age, she has long brown hair and wears a school uniform. She was not present on my first visit but was for the latter three visits. She views her older sister as a role model and is influenced by her behaviour.

Antagonist 2: Rumer age 13 years old, who also looks healthy. She is of slim build, has mousey brown shoulder length hair; she also wears a school uniform. She is the eldest sibling in the family.

Pet dog called Maisie

5.13.2 GEOGRAPHICAL LOCATION

Raff lives in a quiet close near the coast and remote from city areas. An area where there is what his mum refers to as “clean air”. The house was a large detached double fronted house with a porch way and path leading to the front door. There was a double garage to the right hand side with a car parked on the drive.

5.13.3 HOME STAGE SET

As I enter the stage set the family home is spacious. With a large hallway with the stairs to the left plus the door to another room, then on the right was a door leading to Dad’s study and another leading to the kitchen that could be seen through the glass door.

The lounge itself had a wooden floor and there was a large brown thick but soft fabric L shaped sofa in the middle of the room with a rug and coffee table in front of the sofa and a very modern wood burning fire. There was a large piano in the room by the glass patio doors that looked out to a distant sea view.

5.14(5) PROTAGONIST 5 - ERIN

Erin is a 10-year-old girl who looks really well; she looks healthy and well nourished. She is full of smiles and has freckles on her face. She is wearing a headband in her long brown hair and she is wearing a brand new dark blue dress with flowers on. Erin was quiet and reserved initially in her manner. She is friendly, caring and has a strong positive attitude. She later became bubblier and liked to tell me about the things she liked. In particular she talked about her love of dancing and singing. She is the youngest child in her family.

5.14.1 GEOGRAPHICAL LOCATION

Erin lives in a house in a quiet close not far from a local school in a built up area about 15 minutes from the coast, 30 minutes from a city centre and 5 minutes from a local town. The house is a fairly modern looking terraced housing association house with dark red/brown bricks and has a small open front garden with a small path leading up to the door way.

5.14.2 FAMILY MEMBERS

Key player: Mum Sandra a single parent (Parents are divorced)

Antagonist: Chloe age 17 (currently transitioning from children's to adult services). Chloe has a very close relationship with her younger sister she is currently in college and gaining work experience in a local nursery.

Other sibling: Brother age 19

The family have several pet rabbits.

5.14.3 HOME STAGE SET

As I entered the stage set I noticed that the hallway leads into the kitchen and to the right was the staircase. I entered into the lounge area, which was to the left hand side of the hallway as you walk through the front door.

The lounge was spacious enough for a three seated and a two-seated settee. There was a nice smell in the air as there was a fragrant red coloured Yankee candle burning; it was neatly placed on the side unit. The lounge was of a modern design with a laminate floor and a rug in the centre of the room. There were lots of pictures on the wall of the children and one of Erin and her older sister sitting back to back.

5.15(6). PROTAGONIST 6 - DAVID

David is a small 10-year-old boy who is of an average build for his size. He has short dark brown hair and he is wearing dark rimmed glasses. He was quiet and pleasant. David has what I can only refer to as “an old head on young shoulders”. Sometimes appears in his mannerisms and vocalisations to be older than his years. He is responsible but sometimes appears sad. He describes himself as an angry child. David is a middle child within the family.

5.15.1 FAMILY MEMBERS

Key players: Mum Louise and her partner Daniel (David has contact with his dad who is a hairdresser)

Antagonist: Brother Henry age 5. Henry is very pale, small and slim, he has dark hair. He is young for his age. His mother states that his behaviour can be erratic at times and David states that he does not get on with his older brother as they constantly argue. He was very lively and vocal during my visits.

Other siblings: Emma age 2 and Ellie age 14.

The family have a pet dog called Scooby.

(Shortly after my third visit the CF nurse informed me that mum and her partner had split up).

5.15.2 GEOGRAPHICAL LOCATION.

David lives in a main street in a valleys community area where everybody knows each other. There are rows of terrace houses and some shops along the main street. David’s house is set slightly back from the road and is out of keeping with the rest of the houses. It is a larger semi detached

house with a front standing surrounded by wrought iron railings. There is a shop next door on the other side and a take away opposite and a river not far away. There is a working mans club just behind the house. It is a small community setting.

5.15.3 HOME STAGE SET

The house has a long hall way with a door to the kitchen ahead and a stairwell. To the left before the kitchen is a lounge diner with a brown carpet, modern furniture and a semi circle swivel chair. The TV is mounted near the large bay front window. There was a set of toys in the far corner of the room in the dining area and a very large chunky oak dining table surrounded by 6 chairs. There was a window to the back of the room that faces out to the back garden/yard. This was an extremely busy stage set and was described by David's mum as being chaotic as she called it, "the mad house" because there were a lot of people coming and going / passing through it because they lived in a small friendly community.

5.16(7) PROTAGONIST 7 - HATTIE

Hattie is an 8 year old, who is one of twins. She has sleek mousy brown hair pulled back in a ponytail and is wearing her school uniform of a blue t-shirt top and a grey skirt. She is of a slim build, but taller and less frail than her non identical twin sister. She greeted me with a smile; she appeared quiet in her demeanour. Her mum Kate introduced her as 'the sensible one' of which Hattie nodded, smiled, giggled and agreed. Hattie is a middle child within the family.

5.16.1 FAMILY MEMBERS

Key players: Mum Kate and Dad Gareth (Dad works, but I was not made aware of his job).

Antagonist 1: Gabbie age 8 (non identical twin sister) she is very tiny and pale. She looks much frailer than her twin sister. She has long blonde wiry curly hair. Her mum states that she has episodes of erratic behaviour. She has poor eating habits. She has recently been diagnosed with additional complications of CF related diabetes. Additionally she has just been diagnosed with pseudomonas colonisation of the lungs.

Antagonist 2: Lara age 12/13. She has long dark hair; has recently been studying cystic fibrosis as a topic in school with her class and has just become more knowledgeable about CF realising what the consequences of the disease means for her. She had some additional complications with her condition recently.

Other sibling: Noah age 5.

5.16.2 GEOGRAPHICAL LOCATION

Hattie lives in a built up suburban area not far away from a city centre with easy links to a major motorway. The house was just off a small close and surrounded by other houses. The house itself is semi detached with double frontage of Georgian type windows either side of the front door. The house was just off a small close and surrounded by other houses. There is a gate leading into an enclosed front garden with a lawn at the front of the house. There is a moveable football net on the front lawn.

5.16.3 HOME STAGE SET

The main stage set was in the lounge area to the right of the hall way and the front door. There was a wooden floor and two leather settees one under the window and one by the side of the wall on the left hand side. To the left hand side of the lounge there was an opening that leads into the dining/kitchen area. The dining area led to a large patio window that let to a neatly designed and looked after garden, with a garden shed and a trampoline in the corner.

In the lounge to the centre of the room was a wood burning fire and a table to the right hand side that had family photos that were from their recent big family holiday to Florida. One of which was Gabbie the 8-year-old twin with CF, she was with the dolphins and another with Hattie also in the water with the dolphins.

5.17(8) PROTAGONIST 8 - ELINOR

Elinor is an 8-year-old girl who has long brown hair; she had big eyes and a sweet smile. She was very articulate and very well mannered. At one

point during one of my visits she described herself as scared. Elinor wore a pair of coloured leggings and a motif tee shirt. She always changed out of her uniform when she got home from school. Elinor likes playing with her Barbie dolls. Elinor is the middle child in her family

5.17.1 FAMILY MEMBERS

Key Players: Mum Eaddie and Dad Lewis (Mum has a job within the church community and dad is the key carer in the family. He gave up his career as a personal trainer to look after the family at home, particularly as there are two children with CF and sometimes Eaddie has to work away. Dad found it hard to cope with working along with the daily routine of the children's treatment, but he engages in activities in the local community, which includes coaching football.

Antagonist 1: Staci age 9 is tall with long strawberry blonde hair. She is very articulate, confident and outspoken.

Antagonist 2: Toby age 6. He is small and fragile looking he has brown hair. (He has recently been diagnosed with additional complications as a result of his CF as he now has liver involvement with portal hypertension and oesophageal varices).

5.17.2 GEOGRAPHICAL LOCATION

Elinor lives in a new build detached house in a semi rural area. The house is in a small narrow cull de sac on a very large private housing development not far from a local supermarket and petrol station. The house is surrounded by similar style houses but of different sizes within the close. The house is stone laded with a porch frontage and has large windows at the front. There is a double garage and two cars parked on the drive. There is a small open plan lawn area at the front of the house, and an enclosed fenced off garden at the back that leads onto a large playing field.

5.17.3 HOME STAGE SET

As I enter the stage set there is a large L shaped hallway with a laminate wood floor. There were four doors off the hallway. One was to the downstairs bathroom, one to the kitchen on the left. Straight ahead was

the door to the dining room and to the right of the L shape was the entrance to the lounge. Between the lounge and dining room was a large wall that was full of framed family photographs. The lounge also had laminate wood flooring, it was a large lounge and the door leading into the lounge is central to the room with a fireplace directly opposite the door. To the left of the door is the family area with a two-seated settee in one corner and a chair beside it. In the opposite corner is another small chair next to a large shelving unit filled with DVD's and computer games. There is also a television unit next to the shelves. There was glass panelled doors that spanned the back of the room that led to a summer room which were there was a settee a coffee table and the room was filled with children's reading books. The home stage set was not static and was altered on each of my visits. The family had a new settee on one of my visits and on another visit the summer room with books changed into a gym room as a running machine was purchased and placed in that space.

5.18(9). PROTAGONIST 9 - NANCY

Nancy is a tall 8-year-old girl with long hair that is partially tied away from her face with the rest of her hair flowing over her shoulders. She is of slim build as is wearing her school uniform a red t-shirt and trousers. Nancy is quiet and shy but is confident in the way that she talks about her days at school. Nancy refers to herself as being a good girl. She is sensitive and easily becomes upset. She appears younger than her age and is not very articulate. Nancy is the oldest of the children in her family.

5.18.1 FAMILY MEMBERS.

Key players: Mum Joanne and Dad Chris (Dad works for a car rental company and mum is a housewife but in the process of setting up an online business)

Antagonist 1: Fabian age 3 is a really tiny little boy with blond hair wearing a school uniform of blue jogging bottoms and a red jumper. He was quiet and shy initially and spends time playing with his dad on my first visit. He seemed to play with toys that involved sweeping, brushing and cleaning during my visits.

Antagonist 2: Brodie age 6 is a small healthy looking boy. He has short brown hair. He is very vocal and has a continuous banter with his older sister, when they are in the lounge stage set together.

The family owns a pet dog.

5.18.2 GEOGRAPHICAL LOCATION

Nancy lives in a valleys area towards the top of a mountain in a newly built end of terrace house in an estate of red brick housing. The houses are almost hidden from the main road and not very easy to find. Nancy's house is set in a large but quiet close, and is directly opposite a set of flats. There is no front garden and the entrance to their home is directly off the pavement. To the side of the house is a paved area, which can be used for parking. To the back of the house is an enclosed garden.

5.18.3 HOME STAGE SET.

Inside the house was a long and wide hallway leading to the lounge, but before the lounge was a kitchen to the right, then a set of stairs and next to the stairs was a downstairs bathroom. The kitchen overlooked the front of the house and the flats that were opposite. On the wall on the left hand side of the hallway were ornaments on a shelf and Christmas decorations on the wall.

The lounge itself was large with a 3-seated settee to the right of the doorway and a two-seated settee towards the end of the lounge. Next to the two-seated sofa was a large beautifully decorated Christmas tree. Opposite the three-seated sofa was a patio window that leads out to the back garden. It was pitch black outside as the nights were drawing in, so I was unable to see out of the window.

5.19(10). PROTAGONIST 10 - ADAM

Adam is a 9-year-old boy who has blonde hair and blue eyes. He is tall and he looks healthy. He smiles shyly; he is caring, funny and has sense of humour. He is a good boy, very polite and he is quiet. He has informed me that he is crazy about football and he loves playing on his FIFA 15 game. Adam is the elder of the two boys living at home.

5.19.1 FAMILY MEMBERS

Key players: Lowri Mum and Dad Anthony

Antagonist: Haydn is 4 years old; he is very slim, small build and has short brown hair. He is pale faced and has what his mum describes affectionately as a cheeky grin. He likes to wind his brother up and play jokes on him.

Sam – Pet dog/ golden Labrador age 7

5.19.2 GEOGRAPHICAL LOCATION

The visit took place in a built up street that was high up in a valleys area with trees and mountain views to the back of the house. Just around the corner from the house are a primary school and a playground again with open views of the fields and mountain. I parked up outside the school and walked up around the corner towards the house. The house itself was a privately owned semi detached in an elevated position with a black wrought iron gate leading into the garden, with a few steps leading up to the front door. There was a small driveway to the left of the wrought iron gate that was spacious enough for the one small red car that was parked there. The house was well maintained from the outside and as I walked through the gates I could see carefully placed garden ornaments leading up to the front door and I could see what looked like fairy lights switched on glistening through the double glazed front glass window. The front door was made of white PVC and had a stained glass window.

5.19.3 HOME STAGE SET.

As I walked into the stage set through the small hallway I could see the stairwell to the left and the entrance to a small open plan kitchen and the visible kitchen table and chairs. I was led to right into an open plan living area with a slightly portioned wall separating two areas of living space and past the portioned wall towards the left/back of the room that was the main living space that faced onto a small conservatory. The house was lovely and warm and homely with a thick cream carpet throughout and a red rug in the lounge (to the left of the partition wall) and two large brown leather settees with a coffee table and lamp between the two where they formed

an L-shape against the wall. The television was switched on and that was in the far corner of the room, near the opening to the conservatory. To the right hand side of the partitioned wall/living space was a fireplace with a mirror above and there a small set of fairy lights lit up in the room.

5.20 CONCLUSION

This chapter has set the scene for the play “Segments of the sibling mosaic” which will present the findings chapters of this research study. It has introduced the key characters as protagonists and their antagonist brothers and or sisters as well as other family members are also mentioned. To provide insight into the sibling world, their home stage set and geographical location was also described, because this will enable the reader to understand the context of the scenes presented in the play.

*“If I had a world of my own,
Everything would be nonsense.
Nothing would be what it is, because everything would be what
it isn't. And contrary wise, what is, it wouldn't be.
And what it wouldn't be, it would. You see?”*

Alice in Wonderland
Lewis Carroll

6. CHAPTER SIX: ACT 1 THE PROTAGONIST AS A DECENTRALIZED SIBLING

6.1 INTRODUCTION

This chapter will present ‘Act 1’ of the play whereby the positional status of the protagonist is highlighted, as their engagement, interactions and co-constructions with family members as well as the researcher/dramaturge are discussed. This ‘Act’ is relevant because sibling positioning was a key theme that was identified in the data analysis of meeting and spending time with each of the protagonists alongside their antagonist counterparts, within the context of their family and their home stage set.

The term positioning/positional status is referred to in this work to represent the protagonists constructed/co-constructed placing and use of space within their familial cultural milieu as a consequence of living with a child with CF, as opposed to referring to ascribed birth order position. However, in some instances there was a delineation of their birth order status due to a younger sibling demonstrating elements of maternalistic tendencies towards their older sibling, which will be discussed later in the thesis. ‘Act 1’ is divided into discursive sub themes of “waiting in the wings”, “left of centre” and “off-stage place sets”, where each sub theme is presented as a scene to demonstrate and discuss the social actors experiences that were encountered.

Within this chapter dramaturge fantasia is also presented as a metaphorical expression to provide greater context, transparency and reflexivity. The first scene will begin with this dramaturgic presentation.

6.2 SCENE 1 PROTAGONISTS “WAITING IN THE WINGS”

Dramaturgic presentation

Each of my 1-hour visits with the non-CF siblings took place after the children had finished their school day between the hours of 4 pm and 7 pm. As I was driving, in some cases some very long distances (up to 4 hours one way), to see each sibling with their family I had an image in my

mind of the pre performance and stage set preparation of each sibling prior to me reaching them. Having already visited some of the children on several occasions my moment of fantasia was built up of a knowing that the children were of school age and I had begun to have an insight into their worlds, their routines and family life and how they presented themselves at our first visits.

6.2.1 SCENE 2 DRAMATURGE FANTASIA

“The school bell rings,

The children pack away their lessons for the day, some children are given homework and some are not.

Chairs are placed neatly under desks as teachers say “its home time”.

The children (protagonists) collect their coats and bags making lots of noise and chatter. Frivolity and laughter can be heard in echoes in the corridor. As they say goodbye to their friends they are collected outside of the school by their mum and in one family by their dad. Protagonists collect their siblings from different classes or different schools and they head for home either walking or by car. The school children know that they have a visitor today, all but one of the 10 protagonists knows. Today is a different day, still a routine with their families, deciding whether to get changed when they get home from school, deciding whether to get something to eat, waiting while their sibling has a treatment for their CF, thinking when should they do their homework, still in their same familiar home space. Some siblings may have wanted to go out to play but choose not to because today something is different, as the protagonists are waiting.... Today THEY have a visitor! The non-CF siblings are waiting in the wings.”

As I drew near to each family home while driving I developed a ritual of behaviour, I would slow down in the car trying to get my bearings and navigate the end stage of my journey, the music would be turned down as if the lower tone would help my concentration to bring my journeys end closer. I would find the house, park the car, turn the engine off and grab

my bag. My researchers bag as well my handbag, a distinction that the children noticed. On arrival at the family homes, some days it was light, a nice sunny day, some days it was dark and freezing cold as I visited at different times of the year. Regardless of the day or the weather when I walked towards each house I could see the sibling “waiting in the wings”. Some children had peering eyes looking through the front window but not with a full presence, a bit like the performers peeping through a tiny gap in the curtain on the theatre stage trying to get a sneak preview of their audience. Some of the children would give me a little wave. One little boy Adam was sat watching from his favourite upstairs bedroom space and some were shadowed behind their mum. On one occasion a child sat alone on a front bench head bowed, shadowed by his family and another was sent out to meet me while the family stayed on their stage set. The commonality was that on the whole the non cf siblings were either left stage, right stage or momentarily off stage, all of which were “in the wings” of their stage sets i.e. their family home/living spaces.

On each visit my car door would close, I could hear the click of the door, then check the blip of my key lock, it was locked with a flash of light the car confirmed it was secure. There was the clip of my heels on the pavement and a strong feeling of anticipation of wanting to see the sibling and their family along with a sense of relief that I had arrived after a long journey. The sounds of my footsteps walking were followed by my knock at the door. The door opens and the dramaturge is invited in.

(In the case of two visits the whole family waited outside to greet me).

I have selected a brief scene from my field notes to demonstrate my first meeting with one of the families:

6.2.2 SCENE 3 MEETING THE PROTAGONIST CALLED ELINOR

I first see Elinor from the lounge window of the house; she looks like she is crouched down. The windows are low so I know that she is not standing

up. I mainly notice the top of her head and her prying eyes. She is at the window looking out for me. She gives a little wave to make sure I see her. I wave back as I move away from my car. As I draw closer to the house the little girl runs away from the window. She has gone to get her mum Eaddie, to let her know I am there. I reach the front of the house I knock on the door and within seconds the door opens. It is not Elinor the child that was waiting for me that answers the door it is Eaddie the child's mum. Eaddie answered the door she had bleach blonde short hair with a pinkie purple streak in it. She appeared very relaxed and laid back in her manner.

She spoke in a northern accent.

(Her accent reminded me of my own past, my northern roots, I was momentarily nostalgic but then remembered my reason for being there)

Eaddie: Hi I'm Eaddie (Eaddie gives a big smile)

AH: and I'm Amie (Smiles)

Eaddie: Come in

Enter the Dramaturge

I entered the hallway and we stopped by the kitchen door as two girls were stood there.

Eaddie: This is Elinor (I recognise Elinor as being the little girl in the window)

Elinor: Looks shy, she just smiles and looks at me.

AH: "Hi Elinor I have come to see you"

Elinor: Gives a shy look but smiles and looks at Staci (Elinor remains silent)

Eaddie then refers to the taller girl standing behind Elinor

Eaddie: This is Anastasia, but we call her Staci. (Staci is the antagonist)

This initial scene was fairly typical of my first meeting with 8 out of the 10 children because the non-CF siblings were waiting for their visitor, for the person that was coming to see them. All of the children were reserved in

their demeanour at our first meeting and only one child came out to meet me because he was sent out to do so, whereas all of the others waited and stood back until they were introduced to me by either one of their parents. Looking out of the window or peering through doorways, hiding behind a parent or other family members, were commonalities of the children. The protagonists were not used to a visitor coming to see them, this was unusual, because visitors normally came to see their sibling because they have CF. There was a mirroring of self for the protagonist in this initial meeting as they are addressed with “hi I am here to see you” while the antagonist looks on, because the protagonist is normally the onlooker. The protagonists were in a place of uncertainty but quietly pleased about their visitor as was demonstrated with the silent smiles and moments of anticipation, but for some they also wanted the approval of their sibling with CF as was observed in the moment when Elinor looks at Staci in the field note extract above. This was similar to Molly drawing attention away from herself when I said I knew her name, she replied “Do you know my sister’s name?” referring to Emma age 3, the little blonde girl with CF.

As the dramaturge enters each family stage set she is ready to meet the protagonists who are going to take part in my study, the siblings waiting in the wings. When I refer to siblings waiting in the wings I do not just mean in the context of them waiting for me, but I also mean waiting perhaps for their moment and waiting to be presented by their parents or spoken to by myself as the researcher. Along with this was waiting to be allowed to take their position by their sibling the antagonist. As a sibling waiting in the wings they had a presence but unless given permission, it was a silent one, a reserved one as the children did not draw attention to themselves. (This reminded me of perhaps the old fashioned saying that I would hear as a child “Children should be seen and not heard” or “Children should not speak until they are spoken to”). This was in contrast to the moving immediately to the front stage position of their antagonist siblings with cystic fibrosis who were curious and made themselves known to me as

were quick to let me know of their centre stage position. This is discussed in more detail below using four examples of the antagonist presentations of self during our meetings.

6.3 SCENE 4 THE ANTAGONIST AS CENTRAL/ FRONT STAGE PRESENCE WHILE THE PROTAGONISTS LOOK ON:

The four examples discussed here are taken from my field notes. All provide individual responses of the antagonist wanting to take a centre stage positioning within their family stage sets. They wanted to take priority over the protagonist and this was typical for 9 of the 10 families. Within each of the mini scenes that are presented, the antagonists were exerting their position and their need to maintain central presence because that was where they normally belong and they did not want to be moved from centre stage.

6.3.1 SCENE 4 (A) HENRY “DO YOU WANT TO SEE ME?”

While I am sat with David on the settee and talking to his mum in the lounge,

David’s brother Henry age 5 runs into the room semi naked having been in the paddling pool and runs over to me while I am sat on the settee. He is full of life and shouted, “Do you want to see me?” “Are you here to see me?” Henry runs up to me and stands directly in front of me while David is sat quietly to my left on the sofa and he does not say anything. David looks sullen with his head slightly bowed.

Within this scene Henry is excited, lively and vocal. He has not met me before but he was keen to engage in conversation and he was upfront about wanting to be noticed as he ran around the living room with only his swimming shorts on. He then ran straight in front of me to ask if I was there to see him. He was not used to people coming to see his brother and normally it was him that was being seen by someone. Henry had assumed and expected me to be there to specifically for him. When he realized my focus was on David he immediately jumped into his mum’s arms, as he remained lively and vocal, she gave him a momentary cuddle,

much to the dismay of David who pulled a face, to show that he did not want Henry to be getting his mum's attention. With Henry's words "Do you want to see me?" and his direct position of being directly in front of me and facing me, as an antagonist sibling he was forward in his approach in asking for central position or letting the dramaturge know that that was his normal place. In this scene Henry wanted to be noticed, he wanted attention and he wanted to maintain his centre stage position. Henry's response was similar to that of Emma age 3 years, who is the antagonist sibling of Molly and Charlotte.

6.3.2 SCENE 4 (B) EMMA AGE 3 SHOUTS: "PINK, PINK, I WANT PINK"

Charlotte, Molly and I are all sat in the lounge stage set of their home and we are talking about the study and making a picture. The two girls speak quietly and appear reserved, calm and are asking questions. Emma enters the lounge, interrupts and asks "cc..can can I do a picture like Molly and Charlotte?" I explain that yes that's okay she can do a picture. Emma see's the colour paper in my research bag and throughout a section of interview with her sisters continually shouts "pink" "pink" "I want pink" Emma is insistent that she wants pink paper to make a picture because pink is her favourite colour. Emma eventually receives the pink paper and the commotion ends and everyone is happy that Emma is settled.

Within this scene Emma was making her needs known and nobody wanted her to be unsettled so she received the pink paper that she wanted and she had the first choice of the variety of colours that were available. Emma was centre stage in expressing her needs and directly asking if she could do a picture as well. This was a sharp contrast from the reserved nature of her two protagonist siblings. She was asserting herself in continually shouting "pink, pink" as she wanted to make sure she had that colour and that she was heard. As a researcher I was conscious to maintain inclusivity, as I did not want to leave anyone out, but as my focus had not been on Emma initially during this scene, she made sure she

became centralised during my visit. Emma was keen to present her completed picture below on my third visit where she talked of the collage being in the lounge and of the patio doors. She also presented herself in her picture as being “In mummy’s tummy” and in being “Out of her mummy’s tummy”.



Emma’s picture of her lounge space.

To further demonstrate the antagonists centre stage position I have provided two additional scenes that demonstrate elements of their acting out behaviour either with their protagonist sibling, other family member which, presented their given expression of self to the researcher. The scene below presents Raffe's sister Rumer who made her centre stage presence and position known.

6.3.3 SCENE 4 (C) “MOVE” “DON’T TALK” RUMER AGE 13 ACTS OUT

As I sat to the left hand side of the sofa in the open spaced lounge, Alice (Raff and Rumors mum) came and sat to the right of the L shape part of the chair. Neil (Raff and Rumers Dad) sat over near the piano to the other side of the sofa and Raff stayed near mum as he was sat next to her.

As Raff sat on the sofa Rumer came into the room and almost sat on him.

She pushed him out of the way and in a loud voice said "MOVE, THAT'S WHERE I AM SITTING, THAT'S MY PLACE". Raff did not say anything he just moved to the arm of the settee and sat there not saying anything with his head held down and he looked sad. Rumer stayed sitting in the place that she had now gained ownership of and Raff stayed seated perched on the arm of the chair.

At some point dad moved out of the room and I had asked Raff if he wanted to sit next to me on the sofa, which he did.

I continued to talk to Raff and I asked him if he had any friends?

Raff stayed silent as his sister started giggling and shouted "FRIENDS" as she laughed and snorted behind her hand. She continued "He has not got any friends" and then she turned to Raff and said, "Who would want to be your friend? Not even (name of child) wants to be your friend" she looked back at me and said, "He doesn't have any friends".

Rumer was removed off stage by her mum Alice and taken to the kitchen to stay with her dad because she continually "acted out" and responded inappropriately to my questions to Raff, but she later returned to maintain her place and ordered Raff to not talk with her words "You don't talk".

The scene above demonstrated a very powerful interaction and it was an upsetting one to watch, as Raff remained inferior to Rumer as she exerted authority over him in what appeared to be a bullying way. This was the most extreme demonstration of acting out behaviour of the antagonist trying to maintain a centre stage position that I witnessed during my visits. Rumer was trying to be in charge and the boss of Raff in saying what he could and could not do, she was also taking away his voice because she was ordering him not to speak and was trying to answer on his behalf with inappropriate words. Raff himself did not retaliate, answer back or stick up for himself, he just accepted his position and waited "in the wings" for his moment if he was allowed it. What was also noticeable was the physical

centre stage position that Rumer wanted to maintain in taking her 'seat' on a centralised space on the sofa and pushing her brother out of the way so that she could be next to their mum. Rumer was also vying for attention, not just from her mum but also from myself as the researcher and she did not appear to like the fact that attention was being placed on Raff. This was also the case with another antagonist sibling called Gabbie.

6.3.4 SCENE 4 (D) GABBIE IGNORES EVERYONE

Gabbie is aged 8 and she is Hattie's non-identical twin sister. She also made her central presence known by drawing attention to her by not engaging in an interactive conversation during my first visit. Instead she sat next to me on the settee without looking up and played on her ipad. Despite requests to "Put that away" she did not answer as she ignored her mum and her two sisters and continued to play a game.

It was noted by her family members that Gabbie was being disobedient and they referred to her as "the rebel" once she left the room. They commented that she was being unusually quiet. Gabbie then went into the kitchen and placed food in the microwave, which gained her mum's attention as she was concerned regarding what she was eating and the centre of attention was focused on her as she was asked "What are you eating" and it was requested "Don't forget to have your creon" and later as she sat in the lounge eating porridge she was asked again "Did you remember the creon?" Her mum then commented to me "She is always hungry". Gabbie then left the room after finishing her porridge to go on the trampoline outside, which she uses as part of her physiotherapy regimen. She slammed the door and then shortly returned looked at everyone and left the room to go upstairs to be on her own. While the focus was on Gabbie, Hattie sat next to her mum "waiting in the wings" for her moment to be drawn back into the conversation.

6.4 WHEN THE FAMILIAR BECAME STRANGE

Each of the antagonist siblings with cystic fibrosis within the study gave a centre stage performance that was almost like a pleading with the

dramaturge as a director, researcher, and spectator to not take away their position, their co constructed place that provided them with an element of security, reassurance and validated their status within the family. Normally when people came to visit they were there to see them. The antagonist was rivaling for attention but it was a rivalry with oneself that was a performance linked to what appeared to be their confusion of the new situation that they found themselves in. They were in a familiar stage set but in a strange situation with the researcher being present and the focus being on their protagonist sibling. Their performances whether long or brief, were powerful and they made their mark like the prima donna because the antagonist knew they normally had a centre stage position within their family.

It is important to make the contrast above in relation to my early observations of the protagonist sibling positioning that occurred at my primary and in some cases secondary visit with each family. It provided a strong insight to the importance of each sibling knowing their position, and it formulated their constructed identity. This occurred through the presentation of self within the family, their relatedness with each other, as well as how they presented themselves as a person, an individual in their own right.

Earlier I mentioned how the antagonists rivalled with the situation of the dramaturge coming to visit their non-CF sibling to recruit them for a study. Their acting out performance was almost a plea for the attention of the dramaturge to place them as the antagonist at centre stage. It was almost like a known key actor pleading with the director to have the main part in a new play because they have always had the central position in other plays and they always play a key character, as they are usually the stars of the show. However on this occasion the director is choosing the one who is usually the understudy because he/she wants to bring a new dimension to the show and attract a new audience. This is similar to what I am trying to

achieve in my own research study by wanting to add new dimensions to the literature, healthcare practice and policy.

6.5 DRAMATURGE REFLECTION

For the siblings with CF I wondered if this need for centre stage with the power and sense of control it can provide, perhaps negates the sometimes lack of control that their diagnosis of the condition can sometimes have over them. Their position then has an influence over the place that the non-CF sibling takes in waiting in the wings.

While the antagonists drew centre stage to undertake their performances and acting out behaviours, the protagonists sat as onlookers, they remained composed, reserved and not phased by what they were witnessing or hearing. Protagonists were the spectators of the show; they did not see the antagonists as intrusive participants, they did not fight with their CF sibling for central position, because they were not used to having it. They let their sibling have their central moment of introducing themselves in their own way. For the non-CF sibling, they did not mind if the antagonist asked if they could be involved in the study and if they were acting out the non-CF sibling ignored or withdrew from their sibling or obeyed the sibling requests of move out of the way or to stay quiet.

The protagonists accepted their sibling's performance and let it unfold and they did not retaliate because they were used to this centre stage identity of the antagonist and they were used to being on the fringes of their stage sets and this was demonstrated in their passive behaviour so as not to upset the equilibrium of family life. The protagonists supported their siblings in putting them first. Although as the dramaturge, it was I that created the instability in sibling positioning and it was I who upset the sibling equilibrium.

Sibling positioning was not just noticeable during my first visits, but it was also presented in later observations and within the sibling narratives that

they presented themselves where they describe positional moments that are referred to as “left of centre”.

6.6 THE PROTAGONIST IN THE POSITIONAL STANCE: “LEFT OF CENTRE”

The siblings in this study were required to create a picture/collage/visual creation to represent the topic ‘me and my family’. Siblings were then invited to talk about their picture so as to inform me as a researcher what their creation represented in relation to the child in the context of their family life, what life was like for them. A narrative dialogue ensued where the siblings talked about their brothers and or sisters daily routines of treatments for their CF. Within their discussions and my own observations during my field visits, the siblings positioning was apparent i.e. where they placed themselves during treatment times. A commonality was that children did place themselves, “left of centre” as they were often observers of the treatments that were being given to their cf siblings. Scene 3 below provides an observation that I encountered during one of my field visits with Raff and his family.

6.6.1 SCENE 5 (A) RAFF SITS QUIETLY AND WATCHES WHILE HIS SISTERS HAVE THEIR NEBULIZERS

Raff, Bonnie, Rumer and Alice

Stage set: Lounge (The dramaturge is a spectator)

Alice: (Raff’s Mum re enters the room)

Alice: “You need your pulmazyme” (CF medication/nebulizer) (Alice refers to Rumer and Bonnie who are behind the L-shaped settee)

Raff: Raff sits quietly on the L-shape settee. He is not spoken to; he just watches his mum and his sisters.

Alice: Walks from the doorway where she was stood to the back of the settee. She sets up both of the nebulizers for Rumer and Bonnie. The girls hover around Alice chatting/ whispering and giggling with each other. They do not engage with Raff.

Raff: Still sits quietly, he looks pale and withdrawn, he just watches and does not speak.

Alice moves and appears from behind the settee with the two small nebulizer chambers that she has now made up with their medication.

Alice: Gives each of her daughters their respective nebulizer “Right Rumer you can have yours in your room”

Rumer: Takes her pulmazyme away to her bedroom.

Alice to Bonnie: “Bonnie you can sit down here and have yours” Alice plugs in the pulmazyme chamber for Bonnie to sit towards the side of the settee.

Bonnie: Sits there for a short while to the side of Raff as she takes her nebuliser.

Raff: Remains silent, just watching his sisters and his mum.

Bonnie: After sitting for a short while says; “No, I am going to sit with Rumer, she told me to go to her room.”

She unplugs herself and leaves the room.

Raff: Just watches

(Family visit 3: Field visit 2)

Within this scene of treatment preparing and giving, Raff is not in a centre stage position, because he is not waiting to have a treatment, as he is not a child with CF. Within the scene his mum is preoccupied in making up the treatments that need to be given at a certain time, because that is their routine. Her focus is on making up the treatment and setting up the nebulizer. She is also preparing the girls in terms of them being ready for ‘Pulmazyme’ time. It is an important aspect of their care that they both have the treatment as part of their prescribed regimen to maintain their health. Bonnie and Rumer are central to this situation along with their mum because they need their treatment. Alice has the parental responsibility to make sure that they get it and the girls hover around her in a central positioning of focus in the lounge area.

Raff is completely removed from this hive of activity and position because he is not a priority at this moment for Alice or his sisters. He is not engaged in conversation or asked to help because Alice sees such a responsibility as being hers, to make sure the girls stay well. Raff is an observer, a spectator of his sisters awaiting their treatment and of them, particularly Bonnie taking the treatment. In this situation Rumer, Bonnie and Alice are all connected in their interactions in their CF management activities. For Raff he is largely disconnected and placed “left of centre” as a spectator on the stage set. He is not involved and not included because his presence is not required at this time in family life. Once both of Raff’s sisters have had their centre stage moment in this scene, they both remove themselves off stage, leaving Raff still sitting their quietly as a passive recipient of the world around him and of events that he has no control over, because his sisters need their treatments along with the parental attention.

This situation of being “left of centre” was not exclusive to Raff as it was a commonality of the other children within this study as can be seen in the narratives by David when he talks about watching Henry have his treatments at meal times:

6.6.2 SCENE 5 (B) DAVID TALKS OF HENRYS CREON

David’s narrative about his brother Henry’s treatment at meal times, David had drawn Henry on his picture and spoke about him during our first interview:

AH: Does he have anything when he has his dinner?

David: Creon

AH: Creon, so he has to have that sprinkled on his dinner does he?

David: No, tablets.

AH: Tablets and how many does he have? Do you know?

David: Four, four or three

AH: Four or three, okay and he has that every

David: Day

(Family visit 3: Interview 1)

Within this narrative David places himself on the fringes of the stage set at meal times as he talks about his brother Henry needing to have his Creon that he is required to have with every meal. In David's family the responsibility for giving his enzymes lies with his mum. From David's narrative, it is apparent that David watches this process of the Creon giving at meal times, as he is able to count how many Creon tablets his brother has. He is also aware that they are tablets as opposed to capsules as well as being aware that his brother has this treatment everyday. At meal times the antagonists are centre stage. The focus is on them due to the need to have specific enzymes as well as the focus of making sure their nutritional status is maintained. Although David did not mention it, CF children need their dietary intake to be monitored at meal times as well as having the Creon, as they do need a high calorie diet. So the protagonists are not likely to be central at mealtimes.

This was something I observed when Elinor's family invited me to stay for dinner at one of my field visits. Elinor was also not central in the mealtime process, the focus was on Toby and Staci, what they were or were not eating and the problems surrounding their eating habits. David also talked of the times when Henry has his physio and how he sometimes watched his mum doing this aspect of Henry's care. Through his observations and sitting "left of centre" he was also able to demonstrate how the physio was carried out, as he patted his own chest to show me what physio was, but he did not really want to talk about it. He just made an emphasis that this procedure was carried out "every, every, every day" and he told me that sometimes he watched. David also gave a demonstration of a cough after he patted his chest. He did not say his brother coughed but when asked did the physio make his brother cough, he just repeated a coughing sound but would not speak. He performed what he had observed but remained silent in terms of providing a description of the procedure.

Being “left of centre” not only related to treatments that the protagonists observe their mothers doing, but also related also to when the CF nurse comes to visit as Charlotte mentioned in her narrative below about her 3 year old sister Emma.

6.6.3 SCENE 5 (C): CHARLOTTE “WHEN THE NURSES VISIT....I DON’T LIKE TO WATCH”

Charlotte: The nurses that come to visit here at the house and I see some of the things that they do, yeah

AH: Like what sort of things do they sometimes do?

Charlotte: Although I don’t like to watch it because Emma doesn’t like the sight of needles, they have this special port, which she calls a wiggle and then she, and it doesn’t hurt her she just doesn’t like the sight of needles.

Emma: No, I don’t like the water part.

AH: You don’t like the water part.

Charlotte: Because they kind of like put the water in. Sometimes they just come for like a check up...

(Charlotte age 11. Family visit 3: Interview 2).

Within this extract from Charlotte’s narrative she is talking about her observer stage presence that she has where she is watching the CF nurses come to the house to do a port flush on her sister’s portacath. She describes that she is witness to an act that she does not like watching. If she had a choice she would prefer not to watch or be a part of it but she knows the procedure has to be done, and sometimes this is when she is present as a spectator. In her reason for not liking to watch she did not put herself first in the situation. She placed Emma first and central to the not liking it for Emma. With her words “I don’t like to watch because Emma does not like needles”. Her sister did not like the procedure and Charlotte supported her in this. What was not evident in the narrative, but had been in discussions with the family and what I witnessed on my clinic

field visit, was the distress that Emma exhibits when she is to have her portocath flushed. Emma becomes very upset, she cries and shouts.

To demonstrate the distress that Emma projects I have provided a scene from my field notes from my visit to the CF clinic.

6.6.4 SCENE 6 (DRAMATURGE BACK STAGE IN THE CYSTIC FIBROSIS CLINIC)

Dramaturge as an observer/ listener

I am sat in the hub room in the clinic, it was a central station for the CF team to base themselves and meet in between seeing patients. There was still lots of activity/discussion, people coming in and out checking emails, making phone calls in the hub room. I was off stage/back stage. After a few minutes I could hear a child screaming and in distress. A child that was on stage receiving centre of attention, attention that she did not want. I was informed it was Emma (Charlotte and Molly's sister). She was screaming incessantly. The screaming and distress lasted on and off for around 25 minutes. I could hear Emma shouting, "No I don't want you" "No I don't want you to do that"

It was upsetting to hear Emma's cries of distress. I did not say anything I just listened.

The respiratory nurse present in the hub room commented: "Even the nurses feel traumatised afterwards, after having done Emma's portacath".

Having witnessed for myself how Emma responds to having her portocath flush, I can only reflect and make the assumption that when Charlotte states that she does not like to watch the nurses doing the portacath, that perhaps it is because of the distress that she observes in Emma as opposed to the portacath flush itself. For Charlotte, being "left of centre" when the nurses visit at home, is an uncomfortable position for her.

For the children in this study, treatments that are being given to their brother and or sister are not always comfortable to watch even it has become though part of everyday life, whether it be a treatment given by the parent or a nurse. Such discomfort can be avoided for the protagonist if they move themselves away into a safe space, which I will refer to as an “off stage” place set. Such positions/spaces were talked about in addition to “left of centre” moments and were noted when analysing the research data. Moments of moving off stage were not just to avoid feelings of unease, but were because they knew it was not their time for attention and they knew they needed to be out of the way. For some children they were sent off stage by their parents or in one situation a grandparent. Situations that relate to an off stage positional presence/space will be discussed in the next section.

6.7 THE PROTAGONISTS POSITIONED IN “OFF STAGE PLACE SETS”

6.7.1 INTRODUCING ELINOR AND THE BARBIE ROOM

A significant place that was off stage for Elinor when her brother and sister are having their daily treatments is her Barbie room. The Barbie room was Elinor’s bedroom that she shared with her older sister Staci. It is a room that is full of Barbie dolls. Elinor and her family talked about the Barbie room during my first visit and the significance of this room. For Elinor the need for Barbie dolls was something that filtered through each of my four visits. It was also something she presented on her picture collage for the topic ‘me and my family’. Elinor’s mum talked about how she was unable to give her younger daughter any attention when it was treatment time because she had so much to do with the medications and the physio. She speaks in the narrative below:

Scene 7 (a) Elinor and the Barbie room

*Eddie to Elinor; “Sometimes you do have to get out of the way don’t you?
Or I can’t give you attention all the time”*

Eddie continues as she talks about general incidents when she is trying to get the CF treatments ready and do the physio and explains how sometimes Elinor will be trying to speak to her at the same time. Eddie demonstrates her frustration for these times when Elinor is shouting to her "mumm, mumm" (Emphasis played on saying the m in mum), her voice changes, it becomes slightly raised and she gestures with her hand as she demonstrates her response as she says "Not now Eli, just not now" and states

"I just need her out of the way".

AH asks Elinor: "What do you do Eli?"

Eli. "I go to the Barbie room and play. Yes I love barbie's and the Barbie room and I have got 64 no 65 barbies and I get them and I go like".... Eli demonstrates acting out barbie's talking to each other. "We have a Barbie house that dad built"....

(Eddie and Elinor. Family visit 1: Field visit 1)

Within this narrative Eddie expresses her need for Elinor to be out of the way at treatment times because it is not the right time to provide Elinor with attention. In this situation Elinor is not centre stage and this is made known to Elinor and effectively she is being told that she needs to be off stage as her presence is not required at treatment times. In being told not now in the tone of voice and gestures that were exhibited by Eddie, Elinor is effectively being sent off stage as opposed to leaving on her own accord. It appears that if she had the choice and was not gestured to be out of the way, she would probably stay in the room with her family. Elinor verifies her position in this extract above as she tells me that she goes to her special room.



(Photograph taken of a Barbie doll living space in Elinor's Barbie house: Family visit 4: Interview 2)

In leaving the room and having to move off stage, Elinor has been resourceful in finding a space where she seeks comfort, distraction and moments of escapism in her Barbie room. She repeatedly talked about the Barbie's and the room for long periods and in depth throughout my four visits and on my last visit she took me to the room itself and showed me the Barbie House that her dad had made. She showed me each of the rooms in the large dolls house. One of the rooms is pictured above. This provides the impression of an idealised place with no negative activity. It can be viewed as a stage set in its own right, depicting a perfect world.

Elinor's demonstrates the use of the Barbie room as a distraction and as a way of maintaining some stage presence as she enters her own fantasy world in her off state place set where she acts out scenes with her dolls. It is here where she also chooses to re-enact what is going on in relation to

her brother and sister's CF and the treatments that they are having, or in relation to an aspect of the CF trajectory that her siblings are on in the present moment. For Elinor such re-enactment is a way of feeling involved and included in the family treatment activities. Elinor re-enacted scenes with her dolls, this occurred whilst I was present. Eaddie also commented that they sometimes overhear her acting out what is going on in the family. Elinor also described and engaged in different play scenes and gave different roles to each of the dolls in my presence. For Elinor an off stage set is not really her place of choice as she would really prefer to remain on stage with the rest of her family, but she has a created space where she feels safe to go to engage in solitary play. Elinor's off stage set is still one she is being socialised into in recognising her positioning and this is demonstrated with her mum's earlier words of "Not now Eli, just not now" "I need her out if the way".

What I noticed when Elinor took me to the Barbie room to show me the dolls house, was a scene in one of the rooms where Barbie was sat alone in a living space with no one around her. The living space was the lounge area and the doll was sat on the settee as you can see from the picture above. In terms of Elinor's re-enactments this scene presented meaning of her solitary moment of being off stage, away from the family and all on her own. What I also noticed was the doll was carefully placed in the lounge as opposed to the bedroom where Elinor's off stage place was, it was as if this dolls house stage set up represented a place where she would prefer to be i.e. in the lounge rather than the bedroom, however the doll still remained alone. I noticed that the doll was not just alone in the room, but in the house as a whole and I wondered if placing the doll alone was representative of a feeling of isolation in relation to her positioning within the family.

Sending the non-CF siblings off stage was also something Amanda; Molly and Charlotte's mum talked about in one of my interviews while Molly and Charlotte remained quiet and listened. She described a situation where

the CF nurses had come into her home to do Emma's intravenous antibiotics. Amanda's dad was looking after the children, while she was at work. She described her father's reaction to the procedure, and even though it was not he doing the treatment he felt protective over the Charlotte and Molly in terms of what they were witnessing in relation to Emma's body with the portacath and her distress as described earlier.

The grandfather became anxious about the situation and had kept saying "Take them upstairs, take them upstairs" meaning Charlotte and Molly. Sending children off stage during some CF treatment situations can be a protective parenting instinct in addition to the fact that attention cannot be focused on them. Charlotte states in the previous section "I don't like to watch", this would suggest her preference of an off stage presence. So perhaps being off stage can shield non-CF siblings from witnessing adversity to protect their emotional status at certain times during the cystic fibrosis trajectory but this can also limit the protagonist understanding of what is going on in their family home and with their chronically ill sibling.

Not all children were sent off stage unwillingly, for some children took themselves away of their own accord. This was certainly the case for Adam and Erin who did not mind taking themselves to their respective bedrooms.

6.7.2 SCENE 7 (B) ADAMS DEN

During my second visit where the focus was on 'getting to know you,' Adam chose to take me to his special place, which I have named Adam's Den. His brother Haydn who has CF accompanied us to the room, but once we entered he left and preceded back downstairs to stay with his mum in the lounge. Adam and I then played FIFA 15 (a football computer game) for the duration of my stay. Whilst playing this game Adam introduced me to these new surroundings that are presented in an extract from my field notes below:

As I walked up the stairs with both Haydn and Adam, Haydn pointed out his room to me,

Haydn. That's my room. Haydn Points to the door to the left at the top of the stairs

AH. Is it? (Referring to Haydn).

Adam. Yeah, that's his room (Adam concurs).

Adam proceeds to take me to his room that was opposite the stairs and slightly to the left. The bedroom door was wide open, straight ahead on the wall opposite the door were two large framed, signed football shirts on either side of the wall separated by a slightly protruding chimney breast. One of the red football shirts was a Ryan Giggs football top. The door to the bedroom was in the far left hand corner of the bedroom and to the right of the door was Adams bed, a raised single cabin bed that needed steps to climb up to and there were some shelves under the bed that had his xbox a small computer and a set of headphones. By the window was a black leather chair placed by the window where Adam could see out and it was between the bed and a large flat screen television where Adam was able to play his games including his Fifa 15. The television was situated just below one of the signed football shirts.

Next to the black comfy chair was a second chair that looked placed for a second person to sit and play games on the Xbox and on the television. The chair was an upright leather covered kitchen/dining chair that looked like it had been brought from downstairs. The chair had been placed there for me to sit.

On the bedroom window was a trophy for a snooker/pool game. Also on the floor was a mini laptop and another set of headphones that Adam pointed out to me.

(Anthony, Adams dad was upstairs while Adam showed me his playing /sleeping space and the door was wide open to his room).

(Adam, Haydn and Amie: Family visit 2; Field visit 2)

I have presented Adam's off stage place set as an example of a non-CF sibling space. For eight out of 10 of the children in this study, the off stage set was their own bedroom where they had created an area that allowed them to just be themselves away from anything to do with CF, the disease and its required treatments. It was not a place that was largely used by their parents or their CF sibling because it was their space where they took their off stage position. A little bit like an off stage dressing room in the depths of the dark corridors of the theatre. For the protagonists there was no star on the door depicting a main character but inside were possessions that represent aspects of their lives that depict their persona and their individuality.

With the help of their parents non-CF siblings create spaces within their off stage room on which to place the things they like, such as a game, a television, a football T-shirt or in the case of Elinor, her Barbie dolls and the dolls house that her dad made especially for her. Being sent off stage or removing oneself off stage to a place of solitude requires compensatory distractions to be present in their room so that the protagonist can be allowed some self-expression, to be themselves and develop their own individuality/persona.

Physically experiencing Adam's off stage position within his place set enabled me to get to know Adam more readily. I noted his younger brother Haydn did not stay in Adam's space, so it was just Adam and I in the room. I could also see what Adam saw in his world and I was able to experience what he did as we played a football game on the computer/large TV screen.

I noted that for Adam his off stage place set was not completely one of isolation in comparison to Elinor, for example, because he had access to remote social contacts. I witnessed his friends popping up on his TV screen as they were tuned in to what he was doing and they could request that Adam joined them for a game if he wanted and equally he could

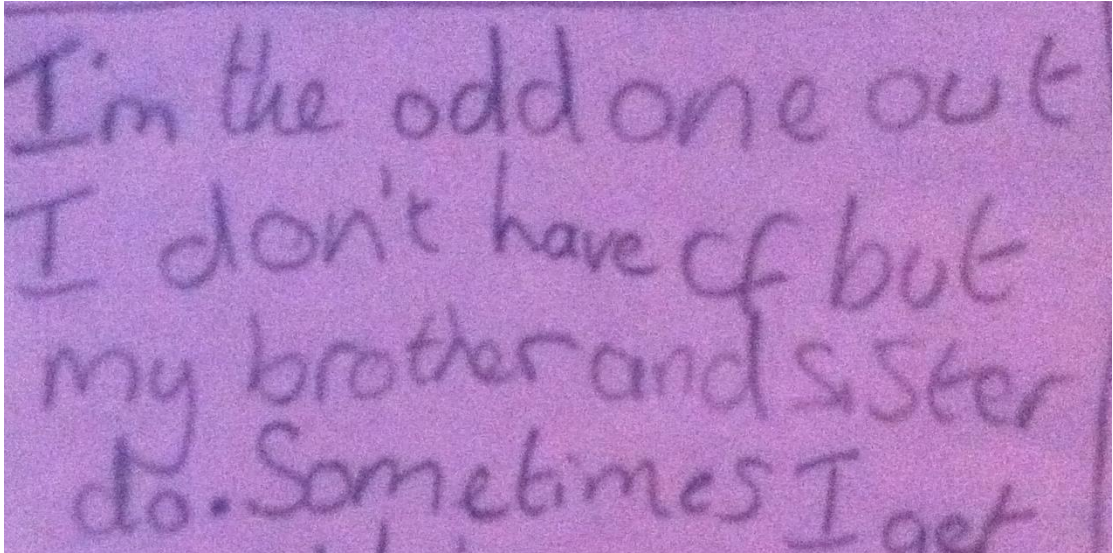
request a game with them. He had several game requests whilst I was there. For Adam his off stage place set was a pleasurable place to go and a space he enjoyed being in it was just like a den and it was free from anything to do with CF treatments. It was also place to go in moments of anxiety or irritation as I recall on a third visit when his younger brother was irritating him, he referred to wanting to go up to his room because his brother was getting on his nerves.

Elinor was able to use her bedroom as an off stage place set even though she shared the room with her sister, but for two children who shared a bedroom with their CF sibling, the bedroom was not a place they chose to spend time. They found alternative places to seek solace off stage. For David he would choose to go out rather than watch his mum do Henry's nebulizer and for Hattie whilst she was left of centre during her siblings treatments in her key place which was the family lounge area, she was the only sibling to have an off stage place where she also had the attention and one to one time with her mum. For Hattie she would choose to go shopping every Saturday and go to a café with her mum for a couple of hours whilst both of her CF siblings were doing gymnastics. This was a strategic choice for Hattie because originally she started gymnastics with her sisters, but then recognized that if she did not go then she would have the one to one attention with her mum in a off stage place, hence placing herself centre stage for two or three hours on a Saturday. She was the only child in the study that moved herself into a central position but this position was not when the children were having their CF treatments.

6.8 CONSEQUENCE OF POSITIONING AND NOT HAVING CF FOR THE NON-CF SIBLING

For the non-CF siblings in this study having a decentralised position within the family due to the treatment requirements required by their brother or sister can lead to consequences as can be seen by the short extract below that was written by Elinor and presented to me during my third visit, along

with her picture. I have specifically chosen to present Elinor's words as she has written them rather than typing them in myself because in her own writing the words provide a powerful message.



(Elinor: Family visit 3; Interview 2).

Within this extract Elinor is making a differentiation between herself and her two siblings who both have CF. She is recognizing that the difference is CF because her siblings have it and she does not. She therefore places herself in the position of the “odd one out”. She feels different because although her younger brother and older sister have a commonality, albeit a chronic illness, that requires the central focus to be around them and their treatments. Their central focus places Elinor in a position of isolation and solitude particularly around treatments times. This can provide the sibling with a lack of sense of belonging and a difficulty in understanding where they fit into family life and how they can fit in. Elinor knows that she is part of a family and is able to identify this sameness in having a brother, sister, mum and dad, but she is also aware that in terms of positioning, things are different for her and it leaves her feeling “the odd one out”. This differentiation is noted by other siblings within my study regardless of whether they have one or two siblings with CF as was noted with Hattie and Charlotte.

When I was talking to Hattie about her picture I asked her “What is it like being you?” And she replied “A bit weird because both Gabbie and Lara have CF and I don’t and they take tablets every day and I don’t”. Hattie is making a distinction here between her siblings and herself. Whereas Elinor states she is the “odd one out” because she does not have CF, Hattie extends the distinction in terms of the treatment taking and requirement of daily management in taking tablets. Hattie demonstrates in her words that she can feel the difference but the only way she can describe it is to say that it is “A bit weird” being her. Both Hattie and Elinor are eight years old and in some ways are still being socialized into knowing their position and are making comparisons between themselves and their respective siblings. For Charlotte age 11 she also raises the peculiarity but brings a further dimension into the equation between herself and Emma her 3 years old sister with CF as during her narrative that was focused around discussing what it was like for her being in her family she stated:

6.8.1 SCENE 8 CHARLOTTE “IT’S DIFFERENT” “BUT THE SAME”

Charlotte: “It’s different because of Emma’s cystic fibrosis but its still the same our parents still treat us all the same and we all get along with each other and it’s quite easy for me to be in my family because I am used to it now”

AH: Because you were not used to it before?

Charlotte: I didn’t really understand it at first but now I do, everything was explained to me.

AH: So what was it like then before you didn’t understand?

Charlotte: I didn’t really know what cystic fibrosis was, anything, because I think I was seven when Emma was born and like a couple of months later we found out she had cystic fibrosis.

(Charlotte: Family visit 3; Interview 1)

Within Charlotte's narrative she provides a contradictory first sentence using the words different and same in relation to being herself, living in her family. She places the distinction of being different in relation to the disease that Emma has and Charlotte does not. She then relates sameness in relation to the way she is treated by her parents but provides a classification of "being used to it now" which suggests that there was a time where she did feel different but has now gotten used to it. It suggests a shift of acceptance in the positioning role that Charlotte has had placed on her because of her sister having CF. She reflects back to when she was seven and when Emma was born and it was at this time she felt things were different and she explained it was due to her lack of understanding of the condition and what was going on with the new addition to her family.

Charlotte's account suggests a shift in her acceptance of her positioning by using the words "used to it now" and suggests that since having everything explained, that she now understands. In terms of her view that her parents treat them the same, this seems to relate more to non-CF care giving activities because earlier within this chapter when I mentioned Charlotte as a spectator of treatments on some occasions where she does not like to watch. I wondered if Charlotte's calm acceptance of her position in the family was due to being socialized into that place through the explanations that she had been provided by her parents. In understanding the explanations she is able to gain a realization of what this means in relation to family functioning. I wondered if this shift of acceptance of her position and saying "I am used to it now" is also because she is 11 years old. With this new understanding Charlotte has developed a level of maturity to which she also takes on a role of occasional helper as she sometimes gets Emma's vitamins and digestive enzymes ready in the morning, but not all of the time because sometimes her mother does this.

Charlotte was the only child in this study to take on an active treatment-giving role as a helper to her mum and a maternal figure to her three-year-old sister. I also noticed her maternalism towards Molly her non-CF sister and how she was trying to socialize Molly into her position, because during my visits if she felt that Molly had stepped out of line, she would openly put her in check as if mimicking her mother. Charlotte was the eldest child in the study.

6.9 CONCLUSION

This chapter has introduced the non-CF siblings as protagonists in this dramaturgic production and in doing so has placed them on centre stage. However, having a centre stage presence is not a reality in the non-CF sibling world as the reader will have noted in the discussions that have taken place in this chapter. The issue of positioning of non-CF siblings within their parallel worlds of their family lives were explored and issues have been highlighted through sub theme of stage positions that deviate from front stage, back stage and centre stage behaviours.

The stage positions of the protagonists have been presented through a lens that places “siblings in the wings”, “siblings left of centre” and siblings in “off stage places”. The exploration and analysis of the data through a dramaturgic lens has identified that in terms of positioning the protagonist siblings are not centre stage or in a central position due to living with a brother and or sister with CF. These siblings are aware that they are not centre stage and this positioning status becomes apparent during the narrative discussions and observations surrounding key CF treatment times.

This lack of centrality it is not hidden, as was demonstrated in the above examples where the siblings observed the centre stage presence of their CF sibling and where they openly listen to their parents stating that the attention cannot focussed on them, because the treatments that the antagonist siblings require for their CF must take priority. These

treatments take time and need to be given on a daily basis and there can be several treatments throughout the day with physiotherapy, medication giving and nutritional management all taking place as well as the constant vigilance of the parent in looking for any deterioration/ changes with their child who has CF.

At these times, for the non-CF sibling they have no control over what is going on around them in relation to the disease or the time consuming treatment it requires. Whilst interventions are taking place, the protagonists are passive recipients to what is going on within their proximity. They cannot change or control what is happening around them, because the disease, as well as the stage of the trajectory that their CF sibling is on dictates treatment requirements. These prescribed treatment regimens can be intensive at times and more so, if there are two siblings in the family with the condition.

Non-CF siblings are in positional stances where they “wait in the wings” or remain “left of centre” when they have visitors or when there are treatments being given and on the whole they do not draw attention to themselves, as they remain quiet or partially hidden. If they do begin to seek attention at treatment giving times, they are quickly socialised back into place, back into a non-central position. This socialisation can take place through a gesture, words or both, from a parenting figure as well as through their own observations in their day-to-day experiences at home. It is important for the family functioning and for the care of the child with CF that non-CF siblings do know or do learn their positional status. They learn that they cannot take priority at certain times because of CF and that there may be restrictions in the family home or within family activities.

On some occasions there is a requirement that the protagonists need to be in an off stage position/place, sometimes they go there of their own accord but sometimes they are sent away. Sometimes they do not want to be sent off stage but are socialised to do so and eventually they just

remove themselves with a knowing acceptance that it is not their time for attention and their sibling must come first. They do not rebel if asked to leave and they do not create, they just accept or they make the decision themselves to leave the room or stay “left of centre”. By not creating or rebelling, siblings avoid upsetting the equilibrium of family life as such actions could lead to chaos and disruption to the focus of the parent and the CF sibling. It could also lead to a negative focus of attention which on the whole non-CF siblings seek to avoid (this will be explored further in the next chapter with siblings being good). It is evident within the child and family narratives that children know their positioning status as not “centre stage”.

What is apparent though is that these children are resourceful and find off stage sets to go where they can create safe spaces. Parents help in the formulation of this space, which is a place free from any CF treatments, a place that will allow self-expression and a suitable distraction or entertainment that will prevent moments of isolation, although sometimes moments of isolation are needed. In having “off stage place sets” these children do become resourceful, creative and develop skills of independence/self-sufficiency in managing their own time and deciding how they spend it, whether it is playing a game, watching TV or remotely socialising with friends until they can join the main family space again when the CF treatments are completed.

As a consequence of their positioning within the family and attention not being placed on them, the non-CF siblings can begin to feel different, left out or like the odd one out. For some children this can make them feel isolated or to experience moments of loneliness as they try to understand the world around them. Particularly for one child a transition has taken place in terms of reaching a level of maturity and taking on a maternal role in medication giving to her sister.

Having introduced the characters and explored the non-CF sibling position within their family through the dramaturgic lens I identified that the siblings with CF can act as an opposing force to the protagonists. This is due to the antagonistic nature of the disease and what this disease trajectory brings into the interactions, social constructions and daily routines of family life, which have an influence over the position status and stage presence of the protagonists within their family. This opposition will be expanded upon further within the next two chapters with discussion surrounding detail within the interwoven themes, subthemes and examples from the data collection that will continue to be discussed throughout this work

“Lastly, she pictured to herself how this same little sister of hers would, in the after-time, be herself a grown woman; and how she would keep, through all her riper years, the simple and loving heart of her childhood: and how she would gather about her other little children, and make their eyes bright and eager with many a strange tale, perhaps even with the dream of wonderland of long ago: and how she would feel with all their simple sorrows, and find a pleasure in all their simple joys, remembering her own child-life, and the happy summer days”

Alice in Wonderland

Lewis Carroll

7. CHAPTER SEVEN: ACT 2: THE IMPORTANCE OF BEING GOOD: AN EXPLORATION OF 'FRONT STAGE PERFORMANCE'

7.1 INTRODUCTION

This chapter will present the second Act, where the multiple interactive performances of the protagonist siblings will be discussed and their narrative performances will be highlighted. The focus of this Act is; "The importance of being good" because when looking through the dramaturgic lens (Goffman 1959) all of the siblings provided multiple presentations of self in their front stage acts in order to give the impression to the researcher of being good. The elements of being good are presented in several scenes to represent the sub themes of "presenting perfect selves", "My idealised family" and "Other ways of being good". In their performances in this chapter, siblings bring their expressions and presentations of self to the stage through a variety of media, which includes; singing a song, costume dress, reading a book, presentation of pictures/collage as well as sibling expression of their wishes. Dramaturgic metaphorical discussion and reflection is also presented as a form of researcher expression and discourse.

In looking through a dramaturgic lens of involving the non-CF siblings in this production the dramaturge has chosen Erin to introduce this section. Erin's has creatively chosen a song to sing, this will be performed, then discussed in a metaphorical sense to set the scene to represent the quintessence of this Act.

7.2 ENTRÉE SCENE 1 ERIN IS MOVED TO CENTRE STAGE TO INTRODUCE ACT 2

The stage curtain opens; today is a getting to know you visit and Erin had wanted to perform the things that she likes to do. She had previously shared that she likes to sing and dance. Her mum Sandra had prompted her with the words "Why don't you do a dance or sing a song for Amie, you said you were going to show her?" Erin responds, "I will sing a song."

Erin is moved out of the wings and brought to centre stage by the dramaturge. She has been called upon to take her place. Erin stands in a centre stage position in her own stage set in her lounge of her home (See Erin's stage set in the previous chapter). The Yankee candle is burning and there is a sweet aroma from the candle in the air. Erin has made adjustments to the stage setting in readiness for her performance. The computer near the window has been set up with the correct music that has been specially chosen and located by Erin. She is ready to begin her performance; she is carefully in position to face the dramaturge and her imagined audience. Her mum is present on stage but more as an onlooker, she sits on the sideline and watches her daughter perform from behind. Erin now looks at the dramaturge and her imagined audience, she is feeling awkward, nervous and somewhat shy and giggly at first, but she wants to perform. This wanting is noticeable by the look that is given in her big eyes and the smile on her face. This is Erin's moment; all is quiet before the performance begins. Her audience is captivated with anticipation. The dramaturge gives a smile and a nod to show that she is ready and then the little girl sings as the music plays:

The song chosen is called 'All of me' by the singer John Legend. Some of the lyrics are presented below:

*I'm on your magical mystery ride
and I'm so dizzy, don't know what hit me, but I'll be alright*

*My head's underwater
But I'm breathing fine
You're crazy and I'm out of my mind*

*[Chorus]
'Cause all of me
Loves all of you*

*Love your curves and all your edges
All your perfect imperfections
Give your all to me
I'll give my all to you
You're my end and my beginning
Even when I lose I'm winning
Cause I give you all of me
And you give me all of you, oh*

[Verse]

*How many times do I have to tell you
Even when you're crying you're beautiful too
The world is beating you down, I'm around through every mood
You're my downfall, you're my muse
My worst distraction, my rhythm and blues
I can't stop singing, it's ringing in my head for you*

As the music fades, so does Erin's voice. She has finished her song and says with a big beaming smile:

Erin: I love this song, I love the words, I play it over and over again, it makes me happy and I am always singing it.

AH: Well done Erin, that was really good. You sang beautifully and you have such a lovely voice. (The audience gives a round of applause for this perfect performance).

(Erin: Family visit 2)

Erin sang the song beautifully and she commented that this was her favourite song. The way she sang was quite moving as you could feel Erin's emotion come through with every word. She put her everything into the performance. When she had finished I asked if she had had singing lessons but she had not. Erin was confident being at centre stage despite her earlier nerves and she does perform in dance groups. What struck me

with this song was the choice of words. Erin was always positive and would put her sister first in all of our interviews/family visits. She would maintain a front stage stance with the most perfect performance even when she was talking about sad things. Erin had chosen a front stage song for her centre stage appearance, but what was apparent was the symbolic importance of her hidden back stage world.

7.3 DRAMATURGE FANTASIA: PRESENTING THE SONG AS A METAPHOR

The way in which Erin sang was very emotive, her expression of the words and tone of voice when singing gave me that goose bump feeling on my arms. I wondered about the words of the song and whether this song was symbolic, a form of expression of Erin's feelings. The song itself is a love song. It is predominantly about a relationship but I could not help but wonder if Erin identifies this song consciously or subconsciously with the interconnected relationship with her sister Chloe who has CF. In exploring the words in a metaphorical sense I wondered about the back stage connotations for Erin:

The words below;

*"I'm on your magical mystery ride
and I'm so dizzy, don't know what hit me, but I'll be alright"*

Almost seem to capture Erin's journey on the rollercoaster of the CF trajectory travelling alongside her sister's journey as it refers to 'I'm on your magical mystery ride.' It is a journey that presents turmoil for Erin through the words 'I don't know what hit me', but she is surviving as she states 'I'll be alright'

The song later talks about all of your 'imperfections' and the lyrics

*How many times do I have to tell you
Even when you're crying you're beautiful too*

*The world is beating you down, I'm around through every mood
You're my downfall, you're my muse
My worst distraction, my rhythm and blues
I can't stop singing, it's ringing in my head for you*

The words are like a symbolic expression of Erin acknowledging that her sister has to go through a lot due to her condition and Erin has talked in her interviews about when she could see her sister not being able to breathe properly or was sleeping a lot. There is a recognition that Chloe is not physically perfect but despite this Erin is there for her, being strong and supporting her no matter what. Erin's words during our visit when she states 'I love this song, I love the words, I play it over and over again, it makes me happy and I am always singing it'. Link to the words in the song 'I can't stop singing it's ringing in my head for you'. It is as if there is something on Erin's mind.

I wondered if the song was also symbolic of Erin's strength particularly when she sang

*'My head's underwater
But I'm breathing fine
You're crazy and I'm out of my mind'*

Normally if your head is under water it would be difficult to breathe but even though there maybe moments where Erin feels or looks like she is sinking, she is saying she's fine, she's strong. She can breathe. She can breathe for herself and wants to breathe for her sister in the moments where she struggles because of her CF. Erin's performance was strong and willful. It was one that was symbolic of trust, strength and an interconnectedness of one of two sisters on a journey through life and through the CF trajectory as Erin sings 'All of me is all of you' means they are together. Erin's performance was one that will always stay with me and not one I will forget. She wanted to please and wanted to shine in her

performance and that she did as she was provided with space to do so, but I could not help but think about the underlying metaphor in her choice of song and Erin's perfect performance.

Erin's song is a bit like past meets present in the prologue of this dramaturgical production only in this case it is where front stage meets back stage where a perfect performance unleashes the hidden with the words that can give the impression to the researcher of representing an internalized presence.

Erin's choice of song along with her performance is representative of all of the children within this study. Her metaphorical recital signifies the importance of looking beyond the front stage presentation to explore the meaning of what lies beneath in the back stage world. This next act will explore the children's worlds within the first key theme presenting perfect selves.

All of the protagonists within this production were viewed as being good children by the researcher as they all presented themselves well and gave some perfect performances some of which will now be explored below.

7.4 PRESENTING PERFECT SELVES IN A "FRONT STAGE STANCE"

On meeting the dramaturge the non-CF siblings knew that they were on stage, they wanted to create a good impression, provide a positive image and to demonstrate their good persona. They executed this through their front stage narratives and actions within their family stage sets. Being asked to be involved in a research study was new to each of the protagonists. They had never been asked or taken part in anything like this before and they were not used to someone coming to see them or someone wanting to provide them with one to one attention in getting to know them. As discussed previously these children were not centre stage in their daily lives, so this was a different experience.

All of the children were eager to be in the study and each one of them when informed that they could drop out at any time replied in a similar way to Erin and Josh who stated “I won’t drop out”, “I want to be involved” and Josh’s mum would state “he won’t drop out, he is always eager to please.” David’s response was slightly different as he stated “I want to help its better than roaming the streets”. For these children they wanted to be involved, to have their moment and to have their say in order to help other boys and girls just like them. In being involved they also wanted to please me and this was evident in their presentation of what appeared to be a construct depicting perfect selves as the siblings upheld their front stage stance. This could be seen in many ways and I have again chosen Erin’s presentation of self for the first discussion in this section. Out of all of the children Erin’s performance was the most consistently a front stage stance throughout my visits. Second to Erin was Charlotte who will also be discussed later.

7.4.1 SCENE 2 (A) : ERIN SITTING PRETTY

Erin enters the room while the dramaturge talks to Erin’s mum Sandra. Erin is wearing a brand new dark colour flowery dress and a large blue headband secures her hair. She is carefully coordinated. The little girl is smiling as her mum introduces her. She proceeds to sit down next to me. She looks perfect, she looks pretty and she smiles a sweet smile. She wants to look nice for her visitor.

(Field notes: Family visit 1)

During this scene Erin was impeccably dressed. She had known that I was going to visit and had planned what she was going to wear, but this outfit was not one out of her wardrobe. It was a dress she had not worn before except for the moments of trying it on in the shop and swirling around in it with positive admiration at the moment of buying it and retrying it on when she got home. This dress was a special dress to Erin, she had chosen it, it was brand new and she had asked her mum to buy it for her especially for me coming to visit. Another had informed me of this.

Erin wanted to create a good image, so she presented a perfect self/ front stage self. She was shy at first and perhaps did not have the words to express herself on that first visit, but words of expression were not needed as she had created an aesthetic image that was pleasing to the eye. She had chosen her costume to give her front stage presence, which gave an impression to the researcher of perfection, by wearing a dress that was socially acceptable and in wanting to be viewed positively at a first meeting in order to create a good impression. Erin's choice of wear was her way of making a powerful statement it was an idealised image that appeared to the researcher as a perfect one. Erin did not wear the dress again in the following 3 visits as she was more able to express herself in words and other acts which were articulate positive ones. Scene 2 reminded me of the nursery rhyme with the words 'sugar and spice and all things nice, that's what little girls are made of'. It portrays the image of little girls wanting to be good and nice.

Presenting the impression of perfect self was not exclusive to the visual in terms of the clothing that a child was wearing but it was also in the words that were spoken and in the acts that were performed. Adam also demonstrates presenting a perfect self in his performance in the next scene. During my visit his mum talked about how the Adam had a good relationship with his brother. Adam agreed with his mum and he informed me that he had bought his brother Haydn a book from the book club from the school the previous day. Adam proceeded to get the book called 'On my farm' from upstairs so that he could read to Haydn. He re enters the stage setting of the lounge in his home and the scene begins:

7.4.2 SCENE 2 (B): ADAM: BROTHERLY LOVE

Adam enters the lounge with the book that he has bought for his brother out of his own pocket money. Haydn is sat on the settee playing with his ipad, Adam sits next to him and moves in close. Haydn puts his ipad down in readiness to acknowledge his brother and engage in the scene of reading time. As both boys have moved next to each other, Adam opens the book and he neatly places it between the two of them and then Adam

asks his younger brother "What does that say?" as he points to the words on the page.

Haydn names the animals on the farm in the book. Where he struggles with a word Adam helps him and at one part of the book Haydn states, "I can't say that there"

Adam responds: "Oh yeah that is too hard, yeah I won't get you to say that" Adam turns the page to another where Haydn can read the words. When the book is finished Adam speaks to me and says: "I only bought him that yesterday and I have read it with him twice already and now that's three times. Adam seemed pleased with himself"

I smile.

Adam stands up and leaves the room to put the book away. Haydn moves back to his original position in the middle of the settee but sits much closer to his mum.

Within this scene Adam is portraying a powerful message of being a good older brother. He provides a perfect front stage performance of which his younger brother is willing to readily engage in because it means he is having one to one attention. Within the scene Adam demonstrates being thoughtful and kind in using his available spending money to buy something for Haydn who has cystic fibrosis rather than buying something for himself.

In this scene Haydn does not put himself first. He demonstrates his connectedness with his brother in moving in closer and taking this time to sit with him. He wants the spectator to know that he cares for his brother, he is willing to spend time with him and demonstrates his patience in teaching him through helping him with the words in the book and not pushing or pressuring Haydn if he thinks the words are too hard. Adam does not engage in any CF treatments or in helping roles in terms of his brother's medication, but he loves and cares for him by sitting and reading. He makes it known that this is not the only time he has read with his brother. Adam wanted me to see this performance; he wanted to act it out

because he could not express it fully in words alone. He wanted give the impression to his audience that he is a good boy and that he wants to do good and be seen to be good.

This was a strong front stage act and it was one that gave the impression of idealized brotherhood. Two bothers sitting together huddled up and close, caring and sharing a moment and a story without any interruptions from CF. The scene gained audience approval with a smile from myself, positive regard from his mum and brother as well as an applause from his imagined audience. Adam looked pleased with the outward approvals where he was reassured that he was being good and being viewed as an older brother looking after his younger brother Haydn.

Haydn was not the only boy in the study to express such brotherly love because Josh age 9 also expressed how he sits with his brother Billy when he has his nebulizer treatment and how sometimes he does not do things such as going to the park, because Billy cannot do them and it would not be fair.

7.4.3 SCENE 2 (C) : “GIRLS ARE GOOD, BOYS ARE NAUGHTY”

It was apparent within my field notes that I used many positive affirmations with the children in this study. Affirmations of praise and encouragement, with the words of “well done”, the children seem to need that, they wanted to be made to feel special, but for one child in this study, she did not always feel special and her front stage performance was a little different than the rest of the children, in that she differentiated being good on the basis of her gender, in being a girl rather than a boy.

For Nancy, who has two younger brothers with CF, girls are good and boys are naughty. Nancy explained on our first meeting that she had been in school and had been crying because the boys at school had been playing and then they hurt her with a branch from a tree. When Nancy was talking about the incident she portrayed herself as the victim and one who is a good girl. She said that ‘the boys (in her school) are always naughty and that they get told off by miss and get sent to the “detention

room” Nancy stated, “That’s were the naughty boys go. The boys in my class are naughty they are always naughty, everyday”. She also refers to her brothers as sometimes being “annoying.”

Presenting herself with the impression of perfect, for Nancy was not being a boy, but a helpless victim who is a girl. She made a distinction with an emphasized differentiation because to her boys are naughty and little girls are good. If you are naughty you get sent to a naughty room and she did not go there. For Nancy, being a girl is being well behaved and that is how she presented her perfect self. However within her front stage generalization about naughty boys, I could not help but feel her sense of momentary isolation. I was not sure if this was because she was a girl without CF with two brothers that had the disease. Nancy demonstrated being a nice girl and caring in her choice of computer game on her ipad, where she talked me through each stage of a game that she was playing where she could wash, change and clothe a baby and in another game look after animals. In presenting perfect self she was showing caring and nurturing behaviours. As she successfully completed one caring/ nurturing task, she could then progress to the next level of the game.

All of the protagonists in the study presented themselves in ways that they wanted to be seen in order to gain a positive regard from their audience. There was an element of guardedness in their demeanor and on occasions they would look to a parent or sibling for a look of reassurance or observe non-verbal cues to make sure that they were saying the right thing. They wanted to protect themselves, as it was important to them to be seen as well behaved children on an individual level. Even Raff presented his perfect self in his silence to not say anything wrong and to remain loyal to his sister who told him not to talk. For Raff being loyal was being decent, because presenting perfect selves was not just about being viewed positively as an individual but it was also important for presenting a perfect family, remaining loyal and protecting their family. Protecting their

family and presenting an idealized family is discussed in more detail in the next section and will draw on evidence from data analysis.

7.5 MY IDEALISED FAMILY

Perfect pictures; perfect families

Presenting an idealized family was something that was particularly demonstrated by nine out of the ten children in this study. This idealization was specifically noted for seven of these children when they were given the task of creating a picture relating to the topic 'me and my family' and for one it was prior to the task. All of the children were asked to create a picture/collage and, or could take photographs to represent the focus above. Children were provided with material of their choice by the researcher, but they could also use their own resources if required. This task was not executed while the researcher was present, but in the interim period between visit two and three. The children chose the time frame in which to do their picture and they were aware that once their creation was complete, that they would then be asked to talk about it in the form of a recorded narrative interview. All of the children were excited about doing their pictures and we talked about the picture project brief, in detail during visit two, where questions that children asked were clarified by the researcher.

7.5.1 SCENE 1: CHARLOTTE'S PERFECT PICTURE

During my visit with Charlotte she sought clarification about her picture as she asked me if she should do a picture of her sister Emma who has CF when she was in hospital. In seeking clarification Charlotte wanted to get things right and she was keen to make sure she was meeting the brief that I was requesting. I did not get the opportunity to respond immediately to Charlotte because her mum Amanda was sat at the table in the dining area and she responded first with the words below

Amanda to Charlotte

“No Charlotte, be positive it does not need to be a picture in hospital. Amie just wants you to do a normal picture. Emma is not in the hospital that often and the nurses come to see her at home”

(Amanda home visit 1)

At that moment Charlotte agreed that she would not create a picture that placed her sister in a hospital or any clinical setting. The expectation was set that this was not what she should do because Amanda had advised her against it as she expressed that Emma is not admitted to hospital now. This was a significant moment within my visit and I wondered about how Amanda’s intrusive suggestion would influence Charlotte. It was as if her mum was being protective and she wanted Charlotte to project the image of perfect family where everything is okay, everything is normal, because that is how she wanted it to be.

When I returned to the family home a few weeks later Charlotte presented her picture, which can be viewed below:



At a first glance of Charlotte’s picture I could see that she had presented all of her family members: her mum, dad and two sisters and her pet dog.

An impression was presented where everyone in the picture was happy and smiling and was coloured in bright colours. Charlotte placed herself in the middle of her two sisters with Emma on the right and Molly on the left. All family members were present on her visual creation. It was not my role to analyse and interpret the pictures that was the role of the child that had created them.

Charlotte had explained that she had created a border to make the picture look like it was in a picture frame like a photo. She wanted to present her picture like a perfect family photograph, but she acknowledged that she had made a mistake when writing 'me and my family' and she felt she had made a mess, so she created a border to hide the mistake. She also talked about how she was not very good at drawing dogs so she asked her friend to help her with the picture because her friend "could draw a good one". Charlotte stated that she had wanted to make it look perfect but she also had been worried that she had coloured the dog in the wrong colour.

What was significant in this situation was that Charlotte presented a creation that at a first glance could be perceived as an idealized perfect family with all of its members being present with happy smiling faces. There was no evidence of CF or the clinical nature of the disease within the picture. I had no preconceptions regarding what each child would present and I aimed to have no influence over their creations except for the chosen topic, which has been stated. However I could not help but notice this wanting of the sibling to create a perfect image of the family. This was not just exclusive to Charlotte as most of the other children in the study created such a perfect vision.

In creating a perfect picture and perfect portrayal of family, Charlotte was demonstrating a positive image that was protective of her and of her family. Charlotte was shielding herself from her actual audience (myself and her own family) and her imagined audience, the outside world. To not

portray a perfect image would be a betrayal of her family who she is loyal to. She does not want to be seen to be telling tales or what she may perceive to be family secrets relating to CF because this would upset the idealized view that she wanted people to have in relation to her family and everything being normal. When I use the term normal here I mean in the sense of not exposing the reality of living within the context of CF.

It could be detrimental to Charlotte if she gained any form of disapproval of the picture presented. In being protective of self and other she was saving face. In presenting an idealized family with the absence of CF in the picture she was protecting her sister and her family from the outside world as well as protecting herself from the inside world that she belonged to. Her concerns were justified because other family members did want to look at where they were placed within the picture and at one point she did have to defend herself and provide clarification to prevent upset within the family. During my visit, 3 year-old Emma came to look at the picture and challenged Charlotte about how she had been portrayed in the picture. Emma did not recognise herself on the creation and mistakenly thought she was placed as the person wearing lipstick to the right side of the dog. With exclamation and distress looking at the picture Emma shouted:

“You’ve given me lipstick and I don’t wear lipstick”. Emma had pointed to who she thought she was on the picture and was informed by her Charlotte who was very quick to pacify the three year old as she stated “That’s not you Emma, that’s mummy” “You are over here look wearing pink your favourite colour.” Emma had been keen to see where she was placed in the picture and had misinterpreted which picture was of her but was happy once her correct portrayal of wearing pink was clear.

Charlotte did not want to cause such distress or chaos and was quick to pacify Emma and show her that she had exposed her favourably and as realistically as possible, without lipstick and wearing pink, because the person with lipstick was her mum. Not only was Charlotte pacifying here, she was also peacekeeping and being conscientious in considering

people's feelings. She did not want such upset or any unbalance in the family equilibrium in the initial presentation of her picture because this would draw negative attention to her, which she would not want. She demonstrated she had done her best with her creation as she recognized what was important to her sister. This was expressed in the picture with the colour pink. A petite figure wearing pink, looking pretty, with blonde hair, situated alongside her sisters, this represented Emma. Emma was not the only child with CF that wanted to identify them in the picture; this was also the case with David's brother Henry who was concerned that he had no hair. David also pacified his brother.

Charlotte did not want to gain the disapproval of her mum Amanda in representing what could be perceived as a false image of her family because Amanda had stated that "Emma does not go to hospital as often anymore." To place any element of CF in the picture would have been disloyal to her mum's suggestion and it was as if she wanted to emulate her mum in everything is okay, everything is normal. In emulating her mum she was also acting as a role model to her other siblings and was becoming socialized into her mums values and beliefs about her family. Charlotte was meeting Amanda's expectations and in doing so she was also gaining positive parental approval and attention that is important to her. Charlotte followed this through further in her responses to her siblings in almost copying her mum's parenting style in keeping her two other siblings in check if she perceived they were not adhering to family values and expectations particularly in relation to talking about CF.

Charlotte wanted to please everyone and did not want to make a mistake in relation to the context or the content of her visual creation and so she created a perfect picture of an idealized family. Charlotte's initial presentation of her picture was a front stage performance that was demonstrated in her protection and shielding of self and family as well as with the avoidance of anything relating to CF within her creation. She extended her front stage performance in pacifying her youngest sister and

demonstrated the correct positioning of her sister. She also met her mum's expectations as well as succeeded in presenting a picture to the dramaturge that fitted the brief of 'me and my family'. The picture alone and the early discussion surrounding the creation did not immediately expose the hidden, the 'what lies beneath the idealization. The front stage position was largely one of protection, pleasing, pacifying and peacekeeping through visual media which all demonstrate the importance of being good.

Initially I wondered about the influence of Amanda's suggestion to not put Emma in a clinic setting within the picture and whether this was the reason for the perfect picture. However, as I progressed through the study I realized that creating a perfect picture/perfect family was not exclusive to Charlotte, as other siblings within the study also demonstrated this. One of these siblings is Erin who had similar traits to Charlotte in relation to idealized family. However for Erin there was an exposal in her front stage performance and presentation.

7.5.2 SCENE 1 (B) ERIN'S PHOTOGRAPH COLLAGE / FRONT STAGE EXPOSE

Erin chose to create a photo board collage for her visual creation relating to the topic 'me and my family' some of which can be viewed below: (Picture not fully shown with photographs to protect Erins identity)



Like Charlotte and five other children in this study, Erin did not want to expose cystic fibrosis in her picture; she wanted to provide a perfect family image. In wanting her picture to be perfect she asked her mum to purchase a large canvas board on which she could place her photographs and generate the image that she wanted to portray. Erin also chose to include happy family events with photographs of pleasant memories in her visual creation. All of the photographs in Erin's collage are of family members that are happy and smiling. The family members include her mum, her brother and her sister Chloe as well as one of the nurses that had looked after Chloe since her diagnosis with CF. Erin saw this particular nurse as being a member of her own family and chose a picture where Chloe and the nurse were taking a selfie when Chloe was in hospital. Erin had cut around the picture so to actually look at I would not have been aware of where the picture was taken and I would not have known she was a nurse, only for the fact that I recognized and knew the nurse which came as a surprise to Erin.

Erin informed me that she had not finished her collage and was only half way through. At a later visit when she had completed it she had included her grandparents from her mum's side of the family. Most of the pictures in her collage focus on happy events, special holidays and perfect spaces. During my narrative interviews Erin speaks with a positive tone and uses positive words as she let me know about the idealization that she wants me to know about. Perhaps an idealization that maybe is what she thinks I want to hear. She uses a careful choice of words and always speaks a knowing caution as her mum Sandra is present in all of our visits and she is very protective towards her mum and would not want to speak unfavourably in anyway. For Erin she is being researched but she is also an active participant to the research process and she wants to do this perfectly.

Within each of my visits Erin's mum Sandra is present on the stage set of the lounge area and is sat on an opposite settee from Erin. Sandra carefully listens to our conversation and the interactive dialogue that ensues and as we speak I watch Erin's non-verbal cues of where she is watching her mum watching her. Each checking the other for reactions and cues, but for Erin this checking is important as she does not want to speak out of turn or to upset her mum in anyway. She is very close to Sandra and all of her family members. This is demonstrated in her recurrent and powerful expressions of love and caring towards them and the repetition of the words that she uses to get her message across. For Erin during the presentation of the picture she wants me to see that she is a perfect sister in her picture because she informs me of situations where she is good and caring. The scene below captures this, but it also captures the moment where Erin's front stage presentation and position is challenged as she is exposed by an 'active informant' who is her mum.

Scene 4 (Stage setting: Erin's Lounge)

The dramaturge is a participant on the stage set, sat alongside Erin on the settee looking at the picture creation. Sandra is sat on the opposite settee.

Erin begins by talking about her brother who does not have CF and she tells me he is 19 now and in the picture her brother was with her on a family holiday.

Erin: We went on holiday in West Harper somewhere I think it was Harper Bay and we just took some pictures there. We went for a week in a caravan (Place names changed here)

I love going in a caravan, its just like when you're in a caravan you get that feeling that you are on holiday and I like it when I am on holiday because I like going swimming because sometimes my cousins come and we all play tennis and have a game of football so I just love being on holiday or something with my family.

Erin: There's my sister Chloe and here's me. (Erin points to a picture of Chloe who has cf and to herself as they are in a picture together)

AH: So what can you tell me about Chloe?

Erin: Well I love being with Chloe because we do, we take care of the rabbits and we go out there (points to the back garden) and when it's nice and hot we'll go out there, get our rabbits out in the pen and it's just really, I love being with Chloe it's just so much fun because she's a really good sister

I asked Erin if there was anything in her picture that she thought she may have liked to add to her but then changed her mind. She responded by informing me that her sister Chloe had helped her just a little bit in creating the picture in terms of putting together their ideas on a drawing pad to plan what the collage would look like. Erin did not answer the question that I

had asked but later her mum Sandra had picked up on this and the conversation can be viewed below:

Sandra: Tell Amie what you was going to put on and you changed your mind.

AH: What were you going to put on?

Erin: Forgot

Sandra: Picture of a (prompting, nodding and looking directly at Erin)

Erin: Oh I was going to put her Kalydeco on (NB: Kalydeco is a new medication for CF that is suitable for around only 5% of people with CF, based on their genotype)

Sandra: That's what you said didn't you, you said oh I might take a picture of her Kalydeco and put that on, that's what you did say didn't you.

(Erin, Amie and Sandra, Interview 1: visit 3).

Initially during this scene Erin was very positive and maintained an optimistic stance in talking about her family holiday in the caravan in West Harper. This included talking about what she likes to do and whom she likes to spend time with. Having the holiday provides a sense of release from her everyday world and provides a different feeling because she knows that she is away in a different environment with her extended family. Erin sustains this affirmative front stage stance as she talks about the relationship with her older sister who has CF. She does not mention CF when initially talking about Chloe but concentrates on her definitive experience of a sisterly bond, where two sisters are together sharing a caring experience of nurturing the rabbits in the garden. This was one of Erin's favourite past times being with her older sister and the rabbits, this bond that Erin talked about in relation to this perfect moment was confirmed when Chloe came home during one of my visits and immediately went out into the back garden to bring a rabbit into the house for Erin and me to see. Moments of being with her sister and her family away from CF were special to Erin. This was her ideal world where

everyone was together, caring, sharing and being loving and it was so perfect.

Whilst Erin had been honest in letting me know that she had asked her sister to help her create a picture because she had wanted them to work together on it, what she did not want me to know was what she did not put in the picture. One of the questions I asked all of the children is; "Was there anything that you wanted to put in the picture that you chose not to?" I asked this question because there is relevance in what has not been included as well as what has and this was the case for Erin. My question provided the first challenge and potential exposure of her exclusion. Within the dialogue Erin initially chose to not answer my question. However Sandra became an active informer in exposing Erin's omission.

Erin was guarded at first and did not want me to know what she had left out of her picture. She chose the word "forgot" to not say because she had not wanted to deviate from the perfect moments that she had been enjoying describing to me. The expose had stopped Erin in her tracks; there was a swift shift from perfection, idealization and happy moments to the mentioning of Kalydeco a cystic fibrosis medication. Erin could see by looking at her mum there was no getting away from mentioning what she had not put in because her mum was reminding her and giving her the encouraging look as if to say "go on, its okay, you can tell". Erin got the cues and did not want to upset or disappoint her mum, or place her in an awkward position and then she went along with the conversation in a more relaxed way than when the initial question "Was there anything you left out? " was first mentioned.

Erin's front stage photograph board and performance was interrupted and exposed but she still maintained optimism when talking about her sister talking Kalydeco and the positive changes it had made for her sister and for the family. For Erin she had not been quite ready to talk about aspects relating to CF as she was enjoying talking about a perfect world of

escapism, her safe space, where she is free from the reality of what having a sister with cf brings into her everyday world. In not placing CF in her picture she was also maintaining a loyalty to her sister who had helped her to plan the board and who had helped her to choose the pictures. Being a loyal and protective sister was important to Erin as well as being a loyal and protective daughter because she wanted to be perceived as a good girl. Such affirmation of being good was essential to Erin's wellbeing and I could see this with the look on her face when her mum spoke of how good she was. I also added to the affirmation in the positive language that I used and the praise that I gave during my visits.

She was the youngest child of three in the family, but within her front stage performance and picture presentation she demonstrated maturity, responsibility and caution beyond her years that would deviate from what one would expect in terms of her age and her birth order within the family. For Erin there was a lot demonstrated in her front stage performance and initial presentation of her picture as can be seen from the discussion above. Her performance was powerful in terms of the unspoken words and picture presented. She was very much contained in her words, actions and emotions. Having front stage demeanor was her way of telling me as the dramaturge and researcher that these are the good things and I am not ready or able to talk about the other things yet. I got the message but I do not think that her mum did. The expose raised an issue sooner that she had wanted, if she had wanted this at all. But within the expose was her mum's acceptance and encouragement that it was okay for her to talk about cystic fibrosis. It was also a reality check that reminded Erin that her sister's treatment for CF was also part of her world as well.

7.5.3 SCENE 1 (C) MOLLY'S FUN DAY

In relation to their pictures of their families both Charlotte and Erin had intrusive prompting from their mothers but this was not the case with Molly when she spoke of her perfect family day where she incorporated her next-door neighbour's as an extension of her family. Her picture can be viewed next:



Molly's picture depicted a bright sunny day where the weather was warm and the families were out in the garden. There was a picture of the trampoline and of the paddling pool in which Molly informed me that her two sisters, their dog and friends from next door were all playing. Molly described how her mum was also dancing with her friend from next door. Her dad was able to do what he liked to do which was watching the sport inside the house (She did not place her dad in the garden picture because he was in the house and Molly informed me that the paper was not big enough to fit the house on too), so everyone was having fun and it was a big happy family day.

For Molly her presentation of her with her family was of being happy, playing and having fun. She described being active and being a good playmate. This particular day was a special one for Molly, it stood out in her mind and it was a day that she felt good being with her family. This day was a meeting of two families, where her friends from next door were over and she considers them to be an extension of her own family. Having such a happy play day was a distraction and a diversion for Molly away from the thoughts of CF and just having fun. This is how she would

like things to always be. In the initial presentation of her picture, her own descriptions did not mention CF. Molly had had a good day and that was her initial focus. For Molly being good and part of a perfect family was having fun and this distracted her from the realities of living in the context of CF.

In relation to the sub theme of perfect pictures; perfect families it is evident that for Charlotte, Erin and Molly that their immediate front stage performance and presentation of their visualisation of 'me and my family' does not portray any evidence of the complexity or chaos ensued in relation to the illness trajectory of CF. This front stage of idealised family was not exclusive to these three siblings but was also the case for David, Raff and Nancy in terms of their picture as they created pictures with happy smiling faces and did not portray any family disruption or provide and back stage insight in relation to living with a brother or sister with CF within their picture. Josh also had a front stage presence but he did not create a picture even though he had wanted to, but his mum had cancelled our appointment.

The sibling's presentation of self and their family in their illustrations are guarded. They were keen to provide an image that they thought that I might like to see or in Charlotte's case, that mum might be happy with, so they place their family in an idealistic way. Such concealment of reality can be a way of protecting themselves and their family in the early stages of the researcher/participant relationship. The siblings presenting the pictures were also aware that other family members may want to view their illustration so were cautious in their endeavours to not display any flaws because it could have a detrimental impact on the sibling themselves or a family member and this was to be avoided at all costs. Such avoidance was conducive to being good to not cause upset and to maintain positivity. This falls in line with presenting a perfect family and how each member wants to be viewed, which is further discussed next.

7.6 SCENE 2(A) PERFECT PICTURE/ ACKNOWLEDGING CYSTIC FIBROSIS

Not acknowledging or presenting any aspect of CF within their picture creation was not the ultimate marker point of whether a child wanted to be perceived as good as opposed to not good. It was whether including CF or not was congruent with family values and socialization of what was acceptable or not acceptable and whilst each sibling aimed to please the dramaturge. It was more important to please their family and in doing so keep the peace.

This was something that became evident as I progressed further into my study. So in contrast to the previous children mentioned above where the siblings chose or were influenced not include anything relating to CF in their picture, three siblings did the opposite and did acknowledge cystic fibrosis so as to be perceived as being good. Hattie, Elinor and Adam, all included aspects of CF in their perfect family picture because they were allowed to. They knew it would not cause upset or condemnation if CF was not included but to the contrary if it was not acknowledged they may feel they would gain disapproval or were not being respectful to their brother and/or sister.

Elinor's picture can be viewed on the next page:



In the case of Elinor she created a picture collage that included things that each member of the family liked. For example she included a monkey because her mum liked monkeys and she included Snoopy and Charlie Brown (cartoon characters) to represent hugging because Eli and her dad like hugging. She also placed a picture of 'manga' because her sister Staci likes drawing 'manga' a children's character.

Elinor's front stage demonstrated that she was putting everyone first and considering things that everyone liked before considering herself. It was as if she was containing what she had really wanted to say at this early stage in presenting her creation. She was also demonstrating her persona of putting others first to create a good impression. She did place a picture of Barbie on her picture that she liked, but expressed how she stuck this on the collage because Eli and her sister like to play Barbie's together. Within Eli's picture she was demonstrating her interconnectedness with each member of the family but primarily wanted to please them in showing that she had considered each one of them by placing on the collage a picture of something that they liked. In terms of CF in her immediate presentation of her picture she just placed two CF logos on her picture as

she stated “I have put cystic fibrosis twice because I have a brother and a sister with CF. Two logo’s for two siblings and two lots of CF”.

At the beginning of my visit when Elinor was talking about her picture all of her family members were present and were entering into the dialogue of her choice of cut outs that she had stuck onto her collage. It was therefore important for Eli to maintain a front stage stance because she was on display, her picture was on display and it was open to family discussion and interrogation. Such exposure meant that Eli needed to shield herself and be mindful of how she and her picture would be perceived by her family. In Eli’s family it was important that the words CF were present on her picture.

7.6.1 SCENE 2 (B) HATTIE “ TURN THAT THING OFF, I CAN’T HEAR...”

For Hattie, her older sister Lara age 12 had offered to help her with the ‘me and my family’ picture. Lara drew a picture of her nebuliser and Hattie drew a scenario of a noisy nebuliser that was so loud that she could not here the television when she was sat in the lounge. Hattie did not like the noisy nebuliser and she would turn the television volume up so that she could hear the programme that she was watching.

Presenting this as front stage was acceptable and was almost a way of Hattie imitating her mum because during my initial field visit this was a situation that Hattie observed her mum talking about to me, whilst gaining validation of the situation where Hattie agreed that she did not like the noisy nebulizer and this is stated on her picture with the words “ Turn the neb off”, “I can’t hear the TV” it caused arguments regarding not being able to hear the television. Hattie’s mum had provided some back stage information, but Hattie’s presentation was front stage emulation of wanting to be like mum and gaining positive regard and acceptance from her mum and her sister, although there was a back stage presence in the picture with the statement “I do not like it when they (meaning both of her sisters) go to hospital because I have to stay with my nan”. Back stage

presentation is discussed further in the next chapter, but this picture also depicts the fluctuation between front stage and back stage presentation.

Below is Hattie's picture:



7.6.2 SCENE 2 (C) ADAM "I WANT TO GO AND PLAY"

For Adam he separated his picture into two scenarios' that depicted his mum giving a nebuliser treatment to his brother while he played football with his dad. Even though he had drawn the picture he did not really want to talk about it and exhibited front stage behaviour to demonstrate that. He had just come into the house and I asked if he wanted to take his coat off and he said no because he wanted to go back out to play later. When he showed me the picture he did not want to really engage and said, "I want to go out and play" his front stage was avoidance, as he was not ready to talk about his picture. He wanted to show it to me but it was not the right time for him to talk about it. He had completed the picture and had presented a family for me to see which included cf treatment and at that moment showing me that was enough for Adam. I informed Adam

that it was fine to go back out and play, which he did for a very short while before coming back into the house.

For Adam his mum was an activist for children with CF, she was very knowledgeable and was an advocate for other families and I could not help but wonder if this influenced his drawing on his picture where he showed his mum next to his brother with the nebuliser. Even though he drew the picture that would be acceptable within his family, his front stage was to avoid talking about it because he did not want to.

For the protagonists acknowledging their brother and or sister's CF in their picture creation was because they felt they were 'allowed' to. In choosing what to include and exclude from their picture was influenced by their interconnectedness and their bonds within their family as well as any help that they did or did not receive. In the spoken or unspoken or inherent belonging within their family, siblings maintained a front stage presence that was mindful in considering the feelings of others. Their motivation is to not upset anyone and to not draw negative attention to oneself or placate anyone else. Doing the right thing, is doing a good thing and not only is this protective of the self and the family as suggested earlier. It is also about presenting an idealised self in addition to idealised family in conforming to a role within the family that they are socialised into because the protagonists are eager to please with a front stage presence.

In relation to their creations that they presented the protagonists are defended subjects shielding themselves from those looking in as they demonstrate a concealment of reality of their true feelings in order to protect themselves and other's. They are cautious to exhibit what may be perceived as flaws, until they reach a stage where they are ready to remove their barriers or given permission to do so. That is if they choose to remove them at all. For the protagonists this is their skilful way of creating safe space for themselves within the realms of their family.

7.7 OTHER WAYS OF BEING GOOD

7.7.1 SCENE 3 (A) DRAMATURGE FANTASIA: THE WISHING WELL

The dramaturge gathers each child (the protagonists) from their parallel worlds; she leads them to a large circular wishing well that is built of stone and it stands alone in an empty field. It's a perfect day as the sky is pale blue with an occasional fluffy white cloud floating up above and the sun is shining making everyone feel warm. The children stand in line and wait at the wrought iron gate by the stepping stone path that leads to the well. A gold coin is given to each one to throw into the well as each child has been granted three wishes. "You have been granted three wishes" says the dramaturge "three wishes just for you, and one can be a really special one" she tells all of the children present.

"You can make one big wish and two smaller ones".

The children's eyes widen and their faces light up with large beaming smiles appearing after their momentary look of surprise that is followed by deep looks of thought!

"A wish for me" says one child

"Yes, just for you" says the dramaturge

"But for what shall I wish for" says the child

"Well, that's up to you" the dramaturge replied

One by one the children follow each other as they skip and jump across each stepping-stone until they reach the large water filled well. They gather around and look into the well they can see it is deep, filled with water below and it looks dark and as they laugh, giggle and chat their noise echoes into the well.

The children surround the well each holding their large gold coin and they wait for the dramaturge to speak.

"After the count of three I want you to make your first big wish as you throw in your gold coin but you must shout out what you have wished for"

Each child simultaneously peers down, glancing over the stone built wall as they throw in their coin. As each coin hits the water there is a splash

noise that is caught up with the echoes of the children's voices shouting out their wish;

"I wish for a cure for cystic fibrosis," shout the children. They all make the first same wish! The wish echoes back "I wish for a cure for cystic fibrosis, fibrosis, rosis, sis"

If only the wish could really come true!

7.7.2 SCENE 3 (B) SELFLESS SIBLING

I have chosen this dramaturge fantasia to lead into the next section of this discussion relating to the exploration of front stage behaviours of the protagonists to add to this chapter of the importance of being good. The above account is based on partial fantasy in relation to the setting and all of the children being together to stimulate a theatrical image. It is based on fact in relation to the three wishes that were granted to nine of the ten children in this study as well as sibling response of wanting a cure for CF. It also provides transparency in terms of dramaturgic reflection. This theatrical fantasia is positioned to represent the selflessness of the siblings in this study.

During my family visits I asked nine of the children that if I were to grant them three wishes for themselves, then what would they wish for. Initially the children did exhibit surprise and gave a taken aback look, like Molly, and a clarification of words asking like Molly and Eli "Three wishes for me?" I got the impression that this made the siblings feel special because something could be granted for them to wish for and in that wish there was an element of choice. It was a chance for them to wish for something that they would like. None of the children blurted out an immediate wish instead they took some time to pause and gave some thought to their answer. All of the children answered, although for one child (Raff) his dad came into the room as we were speaking and he gave an answer for Raff that was the same as the other children answered.

The commonality in their answer was their wish for a cure for CF for their brother or sister. For some of the children they made the wish with me when they were on their own and for some they had a family member around them. The wish that they made demonstrated their selflessness in putting their sibling first rather than making a materialistic wish for themselves. The selflessness of the wish was a powerful moment and it was one that recurred as I visited families. Hearing such a wish from a child made me think about the supremacy of having a brother or sister with CF and for the protagonist if only immediate wish to get rid of it so that their brother or sister could be cured. Front stage selflessness can also be a way of hiding how the protagonist feels about the disease and their experience of it in family life. For the protagonist, placing their sibling's needs first rather than their own demonstrates their selflessness as another way of being good.

Such selflessness was not specific to making wishes but it was also in relation to other behaviours that protagonists talked about in terms of their actual engagement with their brother or sister. Being selfless in her actions as a playmate was something that Molly talked to me about during one of my visits. Not only was she selfless, she was also a pacifier and a peacekeeper.

When I was talking to Molly she spoke of her sister Emma age three and she expressed how she plays with her a lot. She initially gave the impression of being a willing playmate as she had previously talked about the times when they go out into the garden together to play on the trampoline. However on this particular day Molly re-enacted a scenario of what happens when Emma wants to play Peppa pig (Peppa pig is a character from a child cartoon program).

7.7.3 SCENE 3 (C) MOLLY IS EMMA'S PLAYMATE

(STAGE SETTING: MOLLY'S LOUNGE)

Molly talking about her sister with CF. Emma was born, like she's like grown up like two, erm three, I started to play with her a little bit but now sometimes she'll go oh but I want to play Peppa Pig and I'm like but now I want to play something else like teachers.

AH: So who'll say I want to play Peppa Pig?

Molly: Emma

AH: Emma and do you not want to play Peppa Pig?

Molly: No

AH: Why not?

Molly: Because, I do like it just a little bit but like in the games we've got these characters and like her cousin only got one leg, we've got tons of Peppa Pigs, she also wants to have the kitties in it and it like makes it more confusing and all. Like so the pigs and cats and they like each other and I don't get it.

You have to play because then she'll just go off in tantrum. (Molly demonstrates Emma having a tantrum and stamping her feet) Molly continues

She goes like this; I want to play Peppa Pig...(emphasis on the language, said in a drawn out way)

AH: She stamps her feet does she? (Meaning Emma, having seen Molly's demonstration of her sister's tantrum).

Molly: Yeah

Amie: And then you give in.

Molly: I say alright then, just for thirty minutes because she like, thirty minutes, because it's like she's three and then she knows numbers like in the thirties. I bet you thirty, and so she like for thirty minutes I'll play Peppa Pig for thirty minutes.

AH: And then do you time it for thirty minutes or do you just play until you finish?

Molly: I just play for say about two minutes and then I say oh thirty minutes is over, I just have a little couple of minutes.

AH: And then you go and do

Molly: And she'll go oh but I haven't passed thirty minutes, it has to be for ages like a hundred hours.

(Molly and Amie: family visit 3: interview 1)

Within this situation Molly is acting as a playmate to her younger sister and she is engaging in play that she would prefer to no longer engage. Molly feels like she has grown out of playing Peppa pig games as she feels this activity is too young for her. She would rather play a game that she feels is more age appropriate and is perhaps considered a more 'grown up game' with the responsibility of play acting of being a teacher. When her sister wants her to play even though Molly would rather play something else she chooses to pacify her sister and play Peppa pig.

For Molly it detracts from what she would really like to do, but if she says no it would mean Emma having a tantrum. This would mean upsetting her sister with CF, which could lead to chaos being caused at home. It is easier for Molly to give in and she is selfless in putting her sister first, but in addition to selflessness she is also pacifying her sister and peacekeeping because she wants to be seen as a good sister. She is keeping the peace for her sister and for herself, to not play with her sister would lead to havoc and she herself could be viewed unfavourably as being selfish which is not how she would want to be perceived, particularly as her younger sister has CF. However she is strategic in her method of negotiation of giving a timeline of how long she will play for. Within her journey of being a good sister she is developing wisdom.

This wisdom of not upsetting a sibling with CF was also demonstrated during one of my earlier visits with Molly. We were talking while her sister

Emma had gone out with her dad. Molly talked to me about her favourite toys and her favourite movie “Frozen” the Walt Disney film. She talked about how she loved it so much and her and Emma both had the dolls from the film. Molly ran upstairs to get the dolls because she wanted to show me them. She brought her own and Emma’s doll into the room. Molly’s doll was based on the character Elsa who has blonde hair and Emma likes the character Ana, so she has the Ana doll with the dark hair. After a little while of talking about the dolls, Molly suddenly stopped talking. She realized that her sister Emma would be soon be home as they had only gone to the supermarket around the corner.

Molly then stated with a quick realisation

“I better take this one back (referring to the doll that belongs to Emma) because if Emma comes back and sees that I have got it she will be mad”. Molly ran upstairs to take the doll back but left her own doll on the chair. Molly demonstrates the wisdom to know what may upset her younger sister and was proactive in ways to avoid such distress.

Molly was not the only child to do this, this was something I witnessed with David who on the whole did not have a good relationship with his brother Henry, but he chose to not antagonize him. During my ‘getting to know you visit’ I asked David if he wanted to play a game or if there were anything he would like to do. Initially he suggested a game and went to go and get one, but then his mum mentioned that the pieces were probably missing from the one he wanted.

David then changed his mind about what to do and said that the only other games with all the pieces were Henry’s. He stood still for a minute with some thought and stated that “Those games are Henry’s, I better not get those”. At the time Henry was not home, but David knew that to prevent any brotherly chaos it was best to not upset Henry. Causing upset to Henry would also upset his mum and it would mean consequences for David. It was easier to not touch the games that belonged to his brother,

as it would keep the peace, it was better to be seen as being a good boy. Being good and keeping the peace is being wise, as is being selfless. In addition to these ways of being good, another child, Hattie also demonstrated wisdom to gain attention through policing her twin sister's cystic fibrosis treatments while they were in school.

7.7.4 SCENE 3 (D) POLICING SIBLING

Policing and monitoring her sister Gabbie particularly around mealtimes in school was something that was expected of Hattie within her family. This expectation was made clear during my visit when Hattie's dad looked across at her when they were sat on the settee and said "She is our little helper, aren't you Hat?" Hattie responded by making it clear that she helped in terms of Gabbie her twin but not her older sister with cf because she was older and went to a different school.

For Hattie during my visits it was evident that she was her mum's extra pair of eyes and ears because her mum did not work in the school so was not able to be with Gabbie during the day. She was an informer to her parents and an ally, particularly to her mum. On several occasions during my visits Kate, Hattie's mum would ask about how Gabbie had been that date or she would enquire about what Gabbie had done. Kate was always concerned about Gabbie's eating habits as well as being concerned about whether Gabbie was taking her Creon (the digestive enzymes that she needed to take with her food) as can be seen in the scene below:

Stage set: Hattie's Lounge

(The dramaturge is an observer)

Kate to Gab: Did you have your Creon in school today? (Gab is in the dining area and Kate shouts to her from the settee)

Gab: Stops eating and gives a blank look at her mum and turns to look at Hattie for a response.

Kate turns to Hattie who she is sat next to on the settee: Did she have the Creon in school?

Hattie to Kate but looking at Gabbie; Well not at first, yes she had it but I had to go and get it because we have got a new teacher for PE and she did not know about the creon. Gabbie did not get it so I went to get it for her.

Kate. So she had it?

Hattie. Yeh, she had it.

(Family visit 2: Kate, Hattie and Gabbie)

Within this situation initially Kate is checking on Gabbie but she does not get a response from Gabbie and turns to Hattie because she knows that Hattie will be an informer and tell her the truth. Gabbie remains blank faced in anticipation knowing that it is pointless her answering for herself because that is not her role and if she did answer her mum would still check with Hattie that Gabbie was telling the truth. In the situation Hattie tells that Gabbie did not get her Creon herself and make the excuse that it was down to having a new PE teacher. However Hattie saved the day and helped Gabbie by making sure that she herself went to get the Creon from wherever it was stored, so that her sister could have it with her lunch. In this situation there was a duality in pleasing her mum in letting her know that Gabbie had the Creon but also in pleasing her sister in providing an acceptable response. In this situation Hattie was loyal to both her sister and her mum and this gained a positive outcome of everyone being satisfied. In this situation a front stage performance was set.

However, whereas some of the children already mentioned in the study chose to not antagonize their CF sibling. For Hattie, the power of being seen as being good in her mum's eyes by engaging in her given policing role enabled her to gain positive attention specifically from her mum and this sometimes did override such loyalty to her twin sister that was viewed above. This was something I again witnessed during one of my visits

when Kate asked Gabbie how school had been that day? Gabbie had looked at her mum and shrugged her shoulder's stating that the day had been fine. Hattie knew otherwise and stopped what she was doing and she knelt up and placed a hand over her face while she whispered something into her mum's ear. This made Gabbie really frustrated and she demanded to know what had been said because she suspected that whatever had been said had been about her. Her suspicions were justified as Kate then turned to Gabbie and asked if she had given away her pencil case and crayons to someone in school that day. Initially Gabbie denied this but eventually it transpired that this is what had happened. Gabbie responded with the words to her sister Hattie "You need to put a gobstopper in your mouth". Gabbie was frustrated and angry, but Hattie was pleased because Gabbie received negative attention but through her pleasing behavioural interaction she herself received positive attention because she had been good and this was validated in her mum's words when she talked about Gabbie getting out of hand and how she has to rely on Hattie because she is the sensible one, but unfortunately on this occasion it had been to the detriment of her loyalty to her sister.

At that point in time for some reason, even though I was present Hattie had felt the need to gain attention in this way and I wondered if it was a front stage act to demonstrate her ways of being good, staying close to mum, being mum's ally and policing her sisters behaviour, that was normal for her in her family with her given role and her given label. To her this way of being good was acceptable as her expected role and she was demonstrating her idealization.

7.7.5 UNASSUMING SIBLINGS

Within this study all of the protagonists demonstrated other ways of being good that were external to their home environment. All of these children were of school age and during my visits they talked about things at school and one of the things that became apparent for all of them was that they were all good boys and good girls in this environment. Despite living in the

context of CF and all that it brings to the family, as discussed in the previous chapter the protagonists appear to be resourceful in their school activities and achievements as well as demonstrating some resilience in being able to function to gain their specific achievements. Throughout the study it became apparent that all of the children appeared to be functioning well at school and this was demonstrated in their achievements and awards that they had gained. However, most of the children were not forthcoming in telling me about their successes, they only did so when they were prompted to do so by their parents, or by a showing of a photograph or a video that the child was in. I also noticed that the children awards were not all displayed in their main stage set area but were in their own spaces of their bedrooms.

The concealment of their achievements can be viewed as a front stage performance because the protagonists are very unassuming as on the whole they do not gloat, brag or tell you readily about their achievements. They do not place themselves primarily in the limelight because to them they are not used to being centre stage as this is not their position in the home, as has previously been established. They await being prompted or to being given permission to do so and this can be seen in some of the examples discussed below;

7.7.6 SCENE 3 (E) DAVID WINS A PRIZE

During my third visit with David after we had just finished talking about his picture creation he was telling me that he was not good at drawing people when his mum prompted David by saying “Tell Amie about that, that potato”. With this prompting David informed me that he had to decorate a potato, but he did not like the way he had decorated it but took it to school because they had a competition and he received a second place prize. I praised David with a positive affirmation of “well done” and I asked him what he had received for a prize, but he gave a mumbled response that was not clear but he confirmed that everyone clapped when he had come second. This prompted me to ask if he had ever won anything else and he stated that he had. On two occasions David had been successful in

gaining a prize for best pupil of the week and was given a certificate. When I asked him where the certificate was or if he wanted to show me, he was immediately dismissive and stated “I don’t know where it is”.

For David whilst he was pleased about his achievement he did not want to make a big thing about it. He did not want to spend too much time talking about it and it was not something that he had readily decided to inform me about as his mother and I had prompted him. He demonstrated avoidance in his language that added to the unassuming nature of his success by stating that he did not know where the certificate was. I got the impression he wanted it to remain hidden and he did not want to show me. I knew that was the end of his front stage performance and it was his way of telling me that he did not want to talk about it anymore. For David it was easier for him to tell me that he was not good at drawing than for him to share his accomplishments.

7.7.7 SCENE 3 (F) ADAM AND HIS BROTHER HAVE AN AWARD

Such prompting of an achievement was also the case Adam. Although in this situation both Adam and his brother with cf gained an award on the same day. Adam informed me that he had been to school on the day that I was visiting and just like David’s mum, Adam’s mum Lowri prompted him with the words

“Tell Amie what happened in school today? You got an award didn’t you? You and Haydn?”

Adam struggled with the words in telling me what both he and his brother had won their awards for and eventually he was helped by his mum to say, “We won an award for family values and co-operation”.

I asked if they had to get up during assembly time and Adam confirmed that they did and everyone had clapped. It transpired that both of the children had received £10 and a chocolate bunny egg. The response of Adam to gaining the prize was different to that of his brother Haydn in that he was going to put his easter bunny to one side and save it whereas Haydn giggled and exhibited his cheeky sense of humour as he said “I am

going to eat mine, I am not waiting til Easter.” Everyone laughed at Haydn with his quick-witted sense of humour and I could not help but notice that Adam took the lesser stance of not getting excited about his prize; Adam was much more reserved even though his mum was proud.

7.7.8 SCENE 3 (G) CHARLOTTE WINS A CONTEST IN SCHOOL

The prompting of achievement was not specific to parents because in Charlotte’s case it was her non-CF sister Molly that raised the issue whilst I was talking to Charlotte. Molly interrupted with the words “She drew that Charlotte did” and brought a picture in a frame that Charlotte had drawn that included the words alongside the picture “We are writers, God’s children, God’s writers”. As Molly showed me the picture I asked Charlotte about it and it was then that she informed me that she had won a contest in school. Having the picture and the words framed was part of the prize. Like Adam, Charlotte was reserved in her manner, but Molly wanted to share her sister’s achievement with me and as a result it transpired that Charlotte had also written a psalm in a book that had been published in their school. Molly brought it down from her bedroom for me to see. Molly did not share her own achievement of also writing a psalm in the same book, but Charlotte informed me of Molly’s psalm.

Molly was more excited about Charlotte’s psalm, which Charlotte reads out aloud, you can read the words with her as they are posted next:

7.7.9 SCENE 3 (H) CHARLOTTE READS HER PSALM (Stage set Charlottes lounge)

CHARLOTTE: My psalm. God is our Shepherd and we are his sheep, he is with us at the darkest times, at the darkest loneliest times and it’s like leading us to his love. God is with us at times of laughter and times of sorrow, I will never be afraid because I know you are close protecting me from harm. Your dear love brings peace on earth, you cleanse me from

sins and forgive me for the sins I have made. Your love is everlasting and is with me until the end.

(Charlotte family visit 3: Interview 1)

Charlotte presented a front stage stance of being unassuming about her accomplishment but with encouragement she moved into a centre stage position and shared the special words that she had chosen for her psalm of choice to go in the book that was published by the school. When Charlotte read the psalm out loud she spoke calmly, quietly and with preciseness. Her words flowed with a poetic resonance and a beautiful perfect performance just like that of Erin at the beginning of the chapter when she sang her song. Charlotte's psalm was powerful and meaningful to her but she did not talk about why she had chosen that particular psalm or why those words were important. Her recital was pleasing to her sister and to the dramaturge and she was happy with this.

Again just like Erin I could not help wonder about the choice of words in the psalm and the fluctuation to a back stage meaning for Charlotte in her front stage choice of psalm and her momentary centre stage performance of reading the words out aloud. The words are pertinent and provided a powerful impression as they are asking for her to be cared for and shielded from harm and it is recognising moments of isolation/seclusion where she would want god to be with her, to know she has company and is not alone at times when perhaps she may feel alone. The words are strong and deep, they are protective and the words express a wanting to be forgiven if she did anything wrong, because ultimately her aim is that it is important to be good.

The protagonists play down their achievements because even though they are pleased they do not want to draw too much attention to themselves that would place them centre stage because this is not their position and to take this position would upset the family equilibrium, so they quietly and calmly acknowledge what they have achieved but it also seems

unimportant. Somehow having a sibling with CF takes precedent and it would not seem the right thing to do to overly emphasise the prizes and awards that they have gained. It was almost as if it was insignificant, it demonstrated that school creates an environment where they can demonstrate other ways of being good that are external to the family environment. It also demonstrates a difference in their positionality within their school environment where they appear to have more centre stage moments as a result of gaining their successes when they are asked to be on stage in assembly when they collect their awards and prizes. In these instants they are momentarily the centre of attention and are given a round of applause from a real audience as they take their gift or certificate from their teacher or head of school.

These moments provide a quiet gratification and a reassurance that they are doing well, they are decent and they are achieving and that they have a purpose. These moments are special but they internalize their pride within the home environment despite the fact that their parents and their other siblings are proud. For the protagonist living in the context of CF there is a containment of their emotion surrounding their achievements, they know that they are being good and that is satisfying enough for them.

7.8 CONCLUSION

This chapter has focused on eight scenes that have highlighted the front stage stance of the protagonists within their family stage sets in order to explore the key theme of 'The importance of being good'

It has demonstrated that for the non-CF sibling they have a multitude of ways of being good and in doing so they present idealisations of perfect in terms of their individual presentation self and their family. They display a strong protectiveness towards family and particularly towards their siblings with CF regardless of whether they have a positive, negative or ambivalent relationship with them.

It was in their performances that siblings have demonstrated a wisdom and maturity beyond their years as they are strategic in metamorphosing in and out of a multiple of roles that they have been socialized into such as policing, helping, pleasing, peacekeeping and being a playmate, so as to avoid any unnecessary disturbance or upset within the family. Within this metamorphosis they are selfless and unassuming and they skillfully find ways to not draw negative attention to them and to not place themselves too much into the limelight as this is something to avoid, because as mentioned in a previous chapter this is not their position and it is not something that they feel comfortable with. That is unless the centre stage is momentary in collecting their awards and certificates for their achievements that they have gained in school. They remain reserved in their celebration of success as they internalize a quiet gratification in knowing that they have done well as they strive to be good. They do not brag or gloat, because quite often they are often more concerned about what they have not done well or are not good at and this dissatisfaction detracts from their successes because they are trying to reach their own idealized expectations of which is to avoid making mistakes.

In presenting front stage ideology and the impressions of perfections discussed, there is a concealment of reality for the protagonists, a hidden, an avoidance of presenting authentic selves, exposing authentic family and a containment of authentic emotions, as they present what is expected and what is accepted within the realms of the family values and beliefs that they are being socialized into. This is because the protagonists are eager to please because it is important to them to be seen as being good because they do not have the disease of cystic fibrosis but their brother and or sister has and until a cure for CF is found, they cannot change the trajectory that they are on, but finding a cure is what they wish for.

What this chapter as also highlighted as a result of several exposes of back stage connotation particularly in relation to Erin's song and Erin's

omission of kalydeco from her picture as well as Molly's skillfulness and Charlotte's psalm is that it is important to look beyond the front stage and the saving face activity of the protagonist. What is needed is to take time to explore further and to find out what lays beneath the front stage stance and that is the role of the dramaturge in presenting the next stage Act.

7.9 DRAMATURGE FANTASIA

The dramaturge sits facing the front of the stage, for some time she has been watching, waiting and interacting with all of the protagonists as she has visited each and every one of them in their homes and she has spent time in their key stage sets. She has gotten to know them and they have begun to get used to her. She has a feeling that something is different today. All of the children are lined up on front of the stage no longer in their parallel isolated worlds where families with children with cystic fibrosis are unable to meet but they are together in mutual connection and something is changing, something is happening.

The dramaturge watches as all of the children take one step forward and one by one they each join hands Charlotte takes Molly's hand and Molly reaches out for Josh taking his hand as he reaches out for Elinor and she smiles at Nancy as she clenches their hands together tight, Raff doesn't speak he just gives a nod then David, Erin, Hattie and Adam all move together. Charlotte takes the lead as she walks down the steps at the centre of the front stage, all of the children follow still holding hands as they move towards the dramaturge and then they beckon her to follow. They walk around the edge of the stage and up some steps to the right where a black curtain is draped; it is partially concealing a locked door that Charlotte reveals. She looks to the children and they all give a mutual knowing look. "It's time" they all say as Molly moves forward to unbolt the lock on the dark door. As the door opens they all move to enter a dark space, but it's okay because they are not alone today and they feel safe. As they go inside their hands separate and they look behind, they are looking for the dramaturge, as they want her to be there. When they see

that she is with them, they all say, "It is time to move back stage. Come on in, we are ready to show you."

It is also time to move on to the next and final act.

“Never say good bye, because saying goodbye means going
away and going away means forgetting”

Peter Pan

J.M.Barrie

8. CHAPTER EIGHT: ACT 3: THE CONTRADICTION: JOURNEYING ALONGSIDE CF

8.1 INTRODUCTION

This next and final Act will take the reader on a journey into the back stage worlds of the protagonists where they experience a parallel voyage within their family alongside their siblings' CF trajectory. To be invited into the depths of their experience where front stage masks slightly slipped or was removed by choice to reveal authentic moments, were not only a privilege but also a challenge as these children opened up and disclosed their vulnerability.

The challenge for me as the researcher was taking away the burden of some powerful emotional moments when I left each sibling, perhaps carrying them with me throughout the rest of the project. Whereas the challenge for the protagonist, was a knowing of when to tell and what to tell in relation to their information giving and in choosing their instants of readiness once they had built up a trusting rapport with the dramaturge. I do not think this rapport and trust would have been possible had I only visited the family on one occasion, because building up a relationship does take time, and for a study such as this it was essential.

During my family visits these authentic moments were divulged either spontaneously by the protagonist in our getting to know you visits with my mere presence of just being there, or as a result of the children being provided with an opportunity to talk in greater detail about their creative pictures, photographs and general narrative dialogue - as some children said "can we just talk?" As a researcher being present and available to spend dedicated time with each of the protagonists over 4 visits provided a platform to give non-CF siblings a voice. One that would be heard loud and clear so it could provide insight to others in relation to their existence of living in the context of CF. In giving voice, I do not just mean in terms of the spoken word, but also in relation to the multiple performances that each child gave. Entering back stage was risky business and this was

something I recognised and aimed to minimise, as can be viewed in the reflection below in relation to being in the field.

As a researcher it was essential for me to maintain a 'safe space' for each child. In creating 'safe space' I was only encouraging the sibling to talk about what they wanted to discuss, what they felt comfortable with and picking up on cues in terms of their words, gestures and body language of when to stop or not to ask. It required skill, constant vigilance and maintenance of a high level of self-awareness that sometimes left me feeling exhausted at the end of a one-hour visit. (Extract from my field reflection).

In terms of revelations shared by the protagonists they were upfront, direct and genuine in their presentation of words, silences and emotions within their overall performance. It was in those moments I knew that they were comfortable with me and were trusting of my presence, which was important. What was noticeable was that the back stage stance of their repertoire was not only powerful but also at times it was a contradiction to the earlier front stage act which gave an impression to the researcher of perfect selves, perfect families living perfect lives that they had wanted me to see. Their back stage revelations demonstrate fractured childhoods, fractured families, emotional consequences (and sometimes even emotional labour) and childhood vulnerability. Such exposition can now be viewed in the scenes below within the focused sub themes of "authentic moments", "then and now" "moments of separation" and "future selves".

Within this final Act there will also be a guest appearance by an older non CF sibling who is not within the age range of the study but it was a guest who took the time to send me emails as she wanted to share her story of being a sibling who has a brother with this disease. She had gained my contact detail from the Cystic Fibrosis Research Forum. The guest will present a moment of when she was informed of her brother's condition

that would be on a par with the age range of the protagonists in this work. She will also describe how this is impacting upon her in later life. The addition of this guest appearance aims to add greater insight into the sibling world. As the dramaturge I can see its addition as a moral obligation, to add greater evidence to this qualitative study.

8.2 AUTHENTIC MOMENTS

I mentioned earlier how children with CF can face many complexities within the disease because it is a multi faceted/multi system disorder. Each child with CF is different and they face numerous challenges at separate time points which can be dependent upon their genotype, their age, their disease progression and management as well their general state of health and well-being. As the CF children progress along the disease trajectory, their non-CF siblings advance on a journey alongside them as they experience/ bear witness to any altered disease status that may require additional intervention for their brother and or sister. Such additional intervention may be required at home or in a clinical setting. It is at these times where there may be upheaval causing chaotic moments within the family due to complications and intricacies of the disease process as a consequence of altered illness requirements. As the protagonists move alongside this journey within their family they are exposed to changes that can give rise to their own emotional turmoil and this was the case for several children in this study, some of whom will share their narratives in the scenes and sub-themes that are presented in this chapter.

8.2.1 SCENE 1 (A) ELINOR IS SCARED:

Stage set Elinor's lounge but the furniture has been changed around and they have a new settee.

This is a particularly long scene and I have chosen to include a large part of the narrative due to the nature of its content with the dialogue that ensues between Elinor and her mum Eadie, with a little input also from her brother Toby. The scene represents the emotional turmoil that can occur when it is presented to a child that their sibling has an altered disease status. In the case mentioned it is an alteration that can occur along the disease trajectory. There were other children as well within the study that also discussed different moments along the route of CF. What was different in this case was that I was there when the protagonist on her family stage set was going through such a transition.

Prior to presenting the scene I will provide my dramaturgic reflection to offer some background into my noticing that something was different when I visited Elinor and her family on this particular day.

Dramaturge reflection

During the period of time between my first and second visit with Elinor, the family had encountered a significant event whereby her younger brother had been admitted to hospital and diagnosed with complex complications relating to his CF.

I had not been made aware of the turn-around in family events that had happened between my first and second visit but I could feel the emotional change as Elinor's mum greeted me at the door. As soon as I entered the family home my own perception started racing as I was picking up on cues faster than my brain could process and my inner voice telling me "something is going on, something is going on" "It's different today, something is not right".

I sensed the initial subdued nature of the family, the tone of voice, their facial expression, the aura that something was different, something had changed. I felt a difference and it did not feel comfortable. Whilst at the same time trying to maintain my self-awareness and not let the family see that I was picking up on these immediate cues. I was conscious to just be my normal self in my greeting and I did not want to influence the natural environment of my visit. This was not an easy task, this concealment of self, but an open presentation at the same time. I would not capture this as falseness as a researcher, but just being so consciously in tune with what is going on that I needed greater awareness to control and maintain my own presentation on my visit today. Perhaps in terms of dramaturgy I was taking a front stage standing point until I could make sense of the environment and what was going on around me.

(Reflection extract from field notes)

Elinor wanted me to know that something was wrong with her brother and that she was concerned, but within her act she was not able to let me know directly. However, she set up the stage set in the way she positioned herself ready for the performance. I noticed that she approached the subject in a round about way and her performance began as she moved across the room.

Elinor came over and initially sat next to her mum Eaddie and then completely cuddled into Eaddie for the rest of the visit. Elinor looked tired today, she was chatty but not as vibrant as my first visit. The rest of my visit Eaddie was sat with her feet up in a relaxed laid back open position on the new large settee and Elinor was completely huddled into her mum who now had her arms around her. At some moments during our conversation, Elinor was sucking her thumb and demonstrating regressive behaviours.

AH to Eli: So how has your day been Elinor? What have you done today?

(Elinor is cuddled into her mum).

Elinor. Well we were doing cartooning in school this afternoon and then miss took me out of the class for 45 minutes because she wanted to know about Toby's liver, so I did not get the chance to finish it.....

A narrative dialogue was then formed between Elinor and Eadie where Elinor raised questions with her mum and demonstrated her worry, her concerns and her limited understanding of Toby's complications. During this dialogue Elinor demonstrated how she was trying to gain further understanding about what was going on. It was at this point that I shifted from participant to observer. I could not help but wonder if prior to my visit when there had been a lot going on, if Elinor had been a passive recipient of events without questioning what was happening. My visit seemed to open the gateway for the significant dialogue between Elinor and her mum. I wondered had I not visited if this opportunity would have arisen for Elinor but this is something I will never know.

Eadie to Elinor: What did the teacher want to know?

Elinor: (looks pale, quiet and sad, talks quietly) About what happens if Toby is choking blood? (She places her thumb in her mouth).

Eadie: I don't think Amie knows about Toby's liver and what has happened since the last visit. You don't know do you Amie?

AH: No, what has happened?

Mum to Elinor. Do you want to tell Amie about it?

Elinor: Nods (providing verification that she wants me to know)

Eadie to Elinor: Do you want to tell Amie or do you want me to tell Amie?

Elinor takes thumb out of mouth: You tell her because I don't know the words.

(I have viewed this as Elinor's narrative as she has asked her mum to advocate for her because she herself does have the expressive vocabulary to explain and she has chosen to be primarily an observer and a listener in this part of her act and she positions herself close to her

mum). However later within the story Elinor does question some of the missing gaps that she is not sure of in relation to the new situation in the family that she now finds herself in. This was a very powerful moment during my visit and within my journey with this family.

Mum talking for Elinor

Mum to AH: We have had a lot going on since you last came. Was Toby well when you last came?

AH: I remember that he was off school on the day of my last visit as he had not been well.

Mum: Well he wasn't well again and he was admitted to hospital for 10 days. Toby had constipation and they did some further tests and he has got more liver involvement with his CF. We knew in the past he had a bit of liver involvement but now it is much worse and he has got something called portal hypertension which is when the blood flow changes and can become pressured and you can get varices which can burst in your oesophagus in your throat.

(Eddie gestures to the throat) and if they burst then they can bleed so it means he has to carry a letter around with him now all the time in case it happens.

In the above extract from my family visit Elinor's Mum spoke so that her daughter could understand, it was like she was talking to me whilst re explaining to Elinor at the same time because Elinor had stated she did not really understand. As the dialogue progressed, Elinor began asking more questions to engage in the conversation as she raised her concerns and worries.

Elinor: But what will I do when he starts choking blood? (Elinor is sucking her thumb, cuddled up to her mum and looking worried and concerned as well acknowledging some responsibility)

Eddie. Well you will need to tell mummy or daddy and then we will phone an ambulance and get him to the hospital, he may have to go to (name removed)....hospital first or another hospital, but I don't think that they will treat him there so it will probably be ...(name removed).....hospital and then he will be taken to the children's hospital. Because that's where we had to travel away to the children's hospital for 10 days and he has seen the CF liver specialist.

Elinor. But what if he is in school?

Eddie. Then you will need to tell the teacher and they will get the ambulance.

Elinor. Will he go in the ambulance to the hospital on his own then? Who will go with him?

Eddie. Well, if mummy and daddy are not there then a teacher will probably go with him and we will meet him there and then mummy and daddy will have to stay with him in the children's hospital.

Elinor's brother Toby shouted from the computer about the ambulance. He was playing on his computer at the other side of the room and it was as if he called out of the wings of the stage.

Toby: What will happen with the ambulance?

Elinor. Well you (to Toby) would need to go in an ambulance and it will take you to the hospital until mummy and daddy can get to the hospital and the ambulance will go fast so that cars move out of the way so that you can get to the hospital.

Elinor looking very upset, her eyes are big, wide and tearful and she continued to suck her thumb on and off. "But who will look after us"? (Meaning Elinor and Staci)

Eddie. Well either mummy or daddy, one of us will be with you and one of us with brother.

Brother Toby shouts again from the computer: It will have to be mummy; she will have to stay with me because she keeps me company when I am not well (despite playing on the computer Toby is listening to the conversation).

Eddie. Well it might not be because it might be daddy because sometimes I have to go to work (Mum is able to take Elinor with her if she is working). So it might not be.

Elinor, But how will they stop him bleeding?

Eddie. They will treat him at the hospital to make sure that they can stop the bleeding so that he will be better, but if he loses too much blood then he will have to be given some blood to replace it.

Elinor. Where will they get that from though?

Eddie. Well sometimes nanna doesn't she? She goes to a place and they take some blood from her, so sometimes people can give blood to make other people better.

Elinor: Just looks, I can see she is trying to gain answers to lots of questions and uncertainty that she has about this new problem she is facing.

Eddie: We have been honest with the children and tried to explain things and we use the right language and words

Eddie: It means now more hospital visits, more monitoring and maybe more investigations that may include having a scope

Elinor: what do you mean?

Eddie: Where they put a camera inside to have a look what is going on.

Elinor: How do they do that, how does the camera get inside?

Eddie: Well there is a little camera at the end of the tube and then they put it in your mouth and then they look inside.

Eddie: Elinor how did you feel when you were talking about things to do with your brother with your teacher?

Elinor: I am scared

Elinor looked exhausted and pale.

Eddie: Do you want to tell Amie any more about that?

I could see that she had had enough

Elinor did not answer and she completely changed the subject to talk about Barbie dolls.

(Eddie, Elinor and Toby: Family visit 2).

Finding out that Toby had had a shift in his disease status within the disease trajectory had been a shock to the family and they were still coming to terms with it. First there was a long admission due to constipation and the addition of the liver involvement. This appeared to have a huge impact on Elinor and I noticed a significant change in her demeanour from how she was on the first visit, where she was bright eyed, happy and chatty to my second visit where she appeared somewhat subdued, troubled and was exhibiting regressive behaviour's of thumb sucking while she was cuddled into her mum when she was sat on the settee.

What was quite significant within this narrative, and of my observation of the whole situation, was that despite Elinor's regression behaviour where her tone of voice changed to baby speak and where she was sucking her thumb whilst cuddled into mum on the settee, was some acknowledgement of her own responsibility within this situation. There was such a mixture of emotions going on for Elinor during my visit. Despite her fear and worry she was acknowledging her own role as a helper first. This was clearly stated as "What will I do when he starts choking blood?" Elinor's first thoughts were how do I help my brother if he becomes unwell. She was considering the surrounding environment and places that Toby could possibly become ill and when she would need to help and this was evident where she mentioned, "What if he is at school?" She wanted to know how she could help if he was at school and appeared satisfied that she could ask a teacher to help but was then worried that Toby would be left alone in the ambulance when she asked the question "But who will go with him?"

Within the narrative Elinor's primary concern is for her brother and what will happen? She uses words such as how can I help him? Who else will help him? How will he be helped? Her questions and concerns demonstrated not only her worry but also her fear of the new family situation that she now found herself in. She is a child of eight years old,

taking on responsibility and concerns for one of her siblings with CF whilst also considering a second sibling with CF too.

Toby having complications adds an additional burden of worry to an existing condition and it goes beyond the realms of the 'normal' role of helping and looking out for her brother with cf that she is used to and has adapted to. Within this narrative, when Elinor realizes that her parents will go in the ambulance or to hospital with Toby, there appears to be a sudden realization or fear of isolation being abandoned or alone with the question raised "But who will look after us?" These words were spoken in a tone of fear. The look of upset in Elinor's eyes that filled with tears was a very emotive moment and she needed reassurance that she and her sister would not be left alone. Now that Toby had additional but rare complications this would mean more hospital visits for Toby and less attention for Elinor. Elinor received reassurance from her mum and she appeared relieved that she would have one of her parents with her if Toby became unwell.

During this conversation Toby himself was happily playing on the computer and appeared completely unphased by the conversation around him, only to interject that he wanted his mother to go to hospital with him when he was unwell. He did not have the same look of upset or worry as Elinor as he appeared more accepting of his situation even though he was only 5 years old.

Within the dialogue between Elinor and her mum it was evident that some of her fears lay with that of the fear of the unknown in relation to her brother's condition and what might happen if he becomes unwell. There was also an apprehensive curiosity in relation to Toby's new diagnosis and what would happen specifically if the oesophageal varices burst. Elinor was asking some direct, emotionally deep and quite relevant questions within the narrative in relation to what would happen if Toby chokes blood? How could the bleeding be stopped? How could blood be replaced if Toby lost

the blood? The questions were articulated as major concerns that weighed heavily in an emotional sense for Elinor in asking them, and for her mum in answering them as well as for me as a researcher listening to the narrative.

These questions were not the normal everyday questions that one would expect to be asked by an eight-year-old child perhaps in a family where there were no siblings with CF or where there was CF but not complications. However on this day, in Elinor's family, she was asking these questions that exhibited her fears: Fear of being alone, Fear of Toby being alone and Fear of being abandoned did seem to be strongly apparent within the narrative dialogue and to try and alleviate her fears, Elinor wanted answers to her questions. She got some answers but in her final moments, and at the end of her back stage performance I do not think her fear was removed. I could see that she felt burdened and weighed down and this was exemplified in her final words on the subject which were "I am scared". I noted at this point that Elinor was looking pale and tired; things had been too much for her. The conversation was exhausting and the fear as well as worry was just too much to bear. She did not want to talk about Toby anymore and she distracted herself by talking to me about her favourite toys, her Barbie's.

For a child age 8 years old knowing that one of her sibling's with CF has additional complications which are very serious if his oesophageal varices burst is a tremendous burden not only to taken on board emotionally but to carry and begin to understand what is happening here in the context of this narrative. The child is faced with an emotional load that she perceives to consist of the need for additional surveillance of her brother as well as additional responsibility, worry and fear in looking after him and looking out for him in order to protect him. This perception is then validated as Eadie outlines ways in which Elinor can help her brother.

This whole narrative demonstrates the emotional labour that is being faced by Elinor and how she is having difficulty dealing with her current situation within her family. She is aware of her role and her duty within the family and wants to be able to make sure her brother is okay but at the same time there is a strong emotional undercurrent and she is trying to make sense of what is happening as best she can within her cognitive stage of development.

8.2.2 DRAMATURGIC METAPHOR : ELINOR'S TORNADO AND THE YELLOW BRICK ROAD!

Elinor's words " I am Scared" made me think of Dorothy the character in the 'Wizard of Oz' where the huge tornado has turned her world upside down, things are not the same and Dorothy seeks to find help from the wizard but she has a long way to go by travelling along the yellow brick road. For Dorothy in her journey to gain help, she meets many characters along the way including the tin man, the lion and the scarecrow while also being faced with the demons of a wicked witch. Metaphorically speaking I could not help but compare this to Elinor in her recent turn of events. Her tornado, which I could feel racing in the air, her worry and emotional labour are added to with her brother's new problem in his CF trajectory. This diagnoses of portal hypertension and oesophageal varices have been added to an already complex condition and it adds to the existing force of CF. Elinor's journey alongside her brother as a non-CF sibling is facing new transitions that are also accompanied by the range of emotions that she is currently experiencing.

Whilst Dorothy successfully faced her own trials and tribulations along the yellow brick road on her fictitious journey to see the wizard to gain the help she felt she needed, for Elinor her journey is not fictitious, it is real, she is just beginning her own journey along a 'yellow brick road' a path of uncertainty where she is now seeking to find the answers to her questions and to try to gain the support that she needs. I felt that I was a witness to the beginning of this journey and also a part of it as a researcher. Within my visits Elinor recognised herself that she needed help as she

specifically stated that her mummy helps her, just like where she was answering the questions in the narrative above. Elinor also stated her supply teacher was helping her too, so she has sought and gained external support away from the family home and she also stated that she had told her supply teacher that I was helping her as well because of the nature of my research project.

Elinor mentioned the word “help” several times during my visits and what I noticed in her situation was the remarkable way in which she sought that help, which will hopefully help her to move towards a more functional adaptation of her family situation.

In terms of exploring this situation through a dramaturgic lens, the space I had been allowed to enter in this second visit was certainly back stage where I was experiencing the reality of the consequences being faced in relation to Toby’s new diagnosis. The front stage curtain from my first visit had been removed and the temporality of a significant moment of transition in family life for Elinor through this very powerful narrative was shared with me. The movement from front stage to backstage was rapid and I felt the acceleration of this powerful shift almost like ‘Alice through the looking glass’ when she fell down the rabbit hole into a parallel world. Within this compelling experience I felt captured within a circle of emotional labour as a researcher, an observer, a listener and a confidante of the narrative being faced.

None of the other children were engaged in such an expressive dialogue as Elinor as they each presented different back stage performances. Elinor’s situation was to the extreme and the other siblings in this study may not encounter such a complication, but still it is part of her journey alongside a brother with CF. Her story was significant as it represents a significant change in her life. For Elinor she wanted her voice heard.

Elinor was not the only sibling to be faced with a significant transition in journeying along the CF trajectory with their sibling. All of the children are constantly transitioning through the interwoven disease presentation but for some there was a greater presentation of back stage presence due to altered disease physiologies because CF is not a static disease.

One of those children was Molly and it was during my final family visit where I had been talking to her and she was in the lounge with her dad and her three year old sister Emma.

8.2.3 SCENE 1 (B) MOLLY SAYS “YOU DON’T KNOW HOW LONG SHE WILL LIVE FOR”

Molly and I were sat on the settee and her dad was sat on the opposite sofa and Emma was loitering around in between the open lounge/diner area. Molly began talking to me as she expressed that she would like to help her sister to understand more about the disease that she has and she would like for her sister to be taught not to cry when she has her port done (the port is used for the intravenous antibiotics).

Molly added that she herself did not know enough about CF and how she would like nurses to help her understand cf as a sibling because she also would like to know more. Whilst she was talking Molly then moved from her position of sitting on the chair to partially standing with her knee resting on the settee. Suddenly after some momentary thought whilst she was looking straight at her three-year-old sister she stated “With bad diseases, well you don’t know how like how long she will live for, and some people can die of that” (meaning CF). Hearing these words from his eight-year-old daughter was too much for Molly’s dad. These words were not expected and they took her dad and me by surprise.

Her dad got up from the settee and looked at me and I looked at dad almost with a mutual knowing, it was not something he had wanted to hear and Molly’s comment had upset and shocked him. Dad momentarily left the room, but returned a few minutes later.

Looking through a dramaturgic lens to consider this back stage performance, Molly demonstrated that in journeying along her sister with CF, she did not really know enough about the disease, as she wanted to know more. This was not something that she had previously talked about with her parents or within her family. For Molly she had given me the impression that she been internalising her need to know, as well as her worry, that perhaps her sister could die from having the disease. She had been concealing her concern as well as her uncertainty about her sister's life expectancy.

Molly was the only child in my study to specifically question or mention life expectancy/dying from CF. Molly wanted to be released from her emotional internalisation and this seemed to link with wanting to release her sister from emotional externalisation where she demonstrates her distress when she is having her port flush. Molly is an observer of these moments, which she finds upsetting and she expresses a want to help her sister and for her sister to be helped to learn not to cry. She also expresses her own need for help. It is her perception that by being helped to know more, she could then become a helper. In raising this issue Molly is demonstrating a maturity in her way of thinking at such a young age and a willingness to take on a responsibility for her sisters CF because she has concerns about Emma's future as she knows she will be continuing on a journey with her, but what Molly would like is for her sister to grow up to be confident and to not cry because this is disturbing for Molly to see. What was also significant within this situation was the parental unawareness that Molly was concerned about her sister's life expectancy and her thinking about the disease leading to death. However they were aware that she was scared in relation to her sister's portacath.

This was evident from her dad's response to Molly's words as well as a later conversation that I had with Amanda, Molly's mum, as she was seeing me out of the house. She expressed how Molly was too scared to get in the shower with her sister due to her portacath because of the way

her sister's body looked and she was afraid that she was going to hurt her sister. According to Amanda this was all a "big shock" for Molly and she expressed how my coming to visit had been really helpful to Molly. Having a researcher visit had enabled her to voice her fears. Molly had expressed her emotional burden of worry in relation to specific aspects of her sister's condition and this was a burden that was also highlighted during one of my family visits with Hattie where it also transpired that she was also experiencing a transition in both of her sisters' cystic fibrosis trajectories.

8.2.4 SCENE 1 (C) ADDITIONAL SIBLING SURVEILLANCE

Hattie's twin sister had recently been diagnosed with CF related diabetes and she now needed to have her blood sugars monitored as well as have insulin everyday. This meant an addition to her already time consuming daily treatments. During my visit I was witness to and partly engaged in conversation between Hattie and her mum talking about this recent change. Mother informed me that Gabbie was now on two lots of insulin per day, and as a result Gabbie had now put on weight. She added that Gabbie was a "monkey", a term that she was using to explain that her daughter did not have good eating habits and she often hides her food if she does not want to eat it, as a result she requires constant monitoring around mealtimes. This meant that more surveillance was now needed by Hattie to monitor and report back to her mum with regards to what her sister does or does not eat in school. In the previous chapter it was highlighted how Hattie demonstrated policing behaviours and was her mum's allie in relation to monitoring whether Gabbie had taken her creon digestive enzymes, but now with the addition of CF related diabetes, Hattie demonstrated that her surveillance and monitoring/policing role had increased. This for Hattie was an increase in responsibility as well as an increased burden for her at school where she watches her sister and at home when she reports back.

Her responsibility is to make sure Gabbie eats enough to keep her blood sugars stable as well as making sure she takes her Creon. This

scrutiny was highlighted during the conversation as Hattie confirmed that her sister had not eaten all her food in school that day, but on this occasion she also tried to stick up for her sister by adding that the food did not taste nice in school. Hattie had knowledge of her sister's treatments and she also corrected her mum when she was talking about her sister's insulin as she stated "Not two insulin" when her mum had mistakenly stated an incorrect dose, what she had meant was that Gabbie has two units of the medication. Hattie was aware of the dosage and gave the impression that she also monitored this. Hattie was witness to her mum's concerns where she stated, "What they're saying is they want to get her diabetes under control because it can affect her chest. Now I never knew that"

Being witness to mum's concern and the knowledge that her sister's chest could be affected only serves to reinforce the need for Hattie to take her responsibility seriously in being a helper to her mum and her sister, even though it is an added burden. Hattie has the wisdom to know that if she did not take on this role of additional surveillance, then it could be detrimental to her sister and to the family.

8.3 SCENE 2 "YOU HAVEN'T GOT CF" / SIBLING RESENTMENT

Hattie did not afford the same scrutiny to her older sister Lara because Lara is older, as mentioned in the previous chapter. Despite this Hattie was witness to Lara's recent gastrointestinal problems and her mother's discussion surrounding this because her sister had recently been admitted to hospital for investigations. As a result her sister was now on additional gastrointestinal medication, which meant when Lara came home from school she was spending longer periods of time on the toilet due to its effect.

Even though Hattie was not too involved in her older sister's surveillance, what she has been involved in was being subject to her older sister's recent comments because Lara had been doing a project in school to explore the disease in more depth. In her exploration she has discovered

some new insights about the long-term consequences of the disease as a life limiting illness. Due to Lara's age of almost becoming a teenager her mum has stated that she has become more rebellious. As a result she has now been displaying resentment towards her younger sister Hattie and if Hattie says anything about CF she will state, "You can't say anything because you haven't got it". Hearing such words can be hurtful to Hattie and this only serves to reinforce her positioning within the family that was discussed in a previous chapter as well as her feeling of "It's weird being me because I do not have cystic fibrosis". In this family the normal had become abnormal.

For Hattie she is observing and experiencing her sister's transition because Lara is gaining new knowledge of CF and she is trying to come to terms with the disease as she approaches a new developmental stage in her life as she moves towards adolescence with a widening natural curiosity of her own illness. For Hattie she will need to learn how to deal with her sister's resentment but her main way of coping seems to be by staying close to her mum. Journeying along the CF trajectory has altered Hattie's relationship with Lara and this was a shift I witnessed. Whereas previously Lara had wanted to help her sister with her picture and she had wanted to sit in on my first visit with the family. However since her admission, commencement of new medication as well as new insights that she has gained from her school project about CF she has shifted to an altered state in her disease trajectory as well as a new knowing of her disease pathway which has led to resentment that has an impact on Hattie. This could make her feel guilty for not having the disease which adds to her already mentioned perception of "being weird" and gives rise to moments of isolation.

Hattie's family are not the only one's going through a change because of CF. Erin's family are also currently going through a transition because her sister Chloe is now 17 and is about to move across from children's services to adult services.

8.4 SCENE 3(A) MY FRIENDS CHEER ME UP WHEN I AM UPSET

Chloe has been under the care of children's services since she was a baby and this has meant that family bonds have been formed with the staff at the hospital. As Erin demonstrated this in her picture collage as they seemed to see some of the nursing staff as being an extension of their own family. For Erin I noticed that she was witness to her mum's concerns and worries in relation to Chloe moving adult services, which can be very different from an otherwise familiar milieu of children's healthcare.

During my visit Erin's mum Sandra talked about how she was struggling with the idea of losing contact with the nurses and how she is also struggling with the idea of Chloe being in hospital on her own as she is normally resident with her daughter. Erin observes her mum talking to me and she just sits quietly and listens as she allows her mum to lead. As Erin hears she takes in the conversation to become a witness to her mum's worries as Sandra states "I am having more difficulty dealing with it than Chloe" a year ago she said (meaning Chloe) "I am not going", "I don't feel ready", "But she is fine now".

In journeying along CF with a sibling it is tough for Erin because not only is she journeying and witnessing her sister's emotional response to transitions, she is also witnessing her mum Sandra's worry. This creates an added burden for her because she just wants everything to be fine and to be perfect but it is not when a back stage perspective is taken. There is a lot going on in her family and in knowing that her mum is struggling, it places Erin in a position of vulnerability as well as a greater place of maturity and protectiveness towards both her mum and her sister which can result in the containment of her own emotions and an avoidance of displaying negative behaviour or feelings, so as not to upset either of them further. This can place an additional emotional burden on Erin as she chooses to not turn to her family when she is upset, but she did tell me that if she is upset, she does turn to her friends. However if her sister is

unhappy she would expect her to turn to her as she states “When Chloe is happy I am happy and if Chloe is not happy then I just try to cheer her up”. I noticed that she did not say if Chloe is not happy I am not happy, but by wanting to cheer her sister up demonstrated an element of dismay and her wanting of everything to be all right. In observing her sister and Sandra’s worries, but not exhibiting or sharing her own, she becomes a passive recipient to what is going on around her during these moments of emotional turmoil within the family. In being passive she is giving the impression that she is internalizing her own emotion, a form of emotional labour in itself. Erin was not the only child to mention being upset when we visited the back stage space.

David talked about his emotions during our three visits, as he was sometimes not very happy.

Scene 3 (b) “I am an angry child”

Like Erin, David found having a sibling with cf difficult. The mere mention of Henry having CF in my first visit evoked a response of fear in David as he flinched away from me, shaking his head and then he stated “No I have not got CF. I don’t like needles”. I noticed that it did not find it easy to talk about his brother’s treatments and he would demonstrate/ act out some things rather than say the words. For example when we were talking about physiotherapy he would show me by patting his own chest. For David he views CF as being negative as well as associating the disease with a clinical procedure. Once he realized that I knew that he did not have cf and that I was there to ask for his help with my research, he settled down. However there were several occasions where he demonstrated his unhappiness with his brother and he talked openly about how they did not always get on. Initially he talked about his youngest sister who was two years old and did not have CF. He stated that she was lovely and kind, and then he compared her to his brother Henry and talked of how she was not like Henry because he can be “annoying”.

I am an angry child: Stage set David’s lounge

David: He's annoying

AH: In what way?

David: He can get me in trouble and things with me.

AH: Does he? Like, doing what?

David: Nasty, calling me names.

David talked about how they share a room but they do not go to bed at the same time because they will fight. The conversation then continued

AH: So what sort of things does he blame on you then.

David: Lots (unclear)

AH: Can you think of an example?

David: If he made a mess, blame it on me.

AH: If he made a mess he'd blame it on you.

David: Yeah

AH: And then what would your mummy say?

David: Clean your room, clean your room. (Referring to David rather than Henry)

AH: So then you have to clear up the mess and then how does that make you feel?

David: Sad

AH: Sad, yeah and then what do you do then?

David: Tidy it up.

AH: Tidy it up and does it make you feel anything else? Just sad and feel like you're being annoyed?

David: Very (Much emphasis was put on the words and his voice intonation changed)

AH: Very

David: I'm an angry child

Within this scene David is describing how he feels that he takes the blame for things that he has not done and in so doing he receives negative

attention from his mum. This is something that he would rather avoid as he strives to be good and would really prefer positive attention. He also feels that the blame placed on him is not justified and he associates his brother as getting away with things and not been checked if he has done something wrong. Henry knows that because of his CF and his journey along the disease trajectory, it is likely that his mum will not want to 'tell him off' or that he can perhaps push his boundaries a bit more than David. For David he is older than Henry and he can see an injustice as well as an unfairness in this situation and he feels that Henry should tidy up the bedroom if he has made a mess. For David in this situation he is the scapegoat of his brother's ills that leads to his frustration, his sadness and his anger.

Something unexpected happened for me when David was talking about this situation and whilst he abruptly ended this scene with "I am an angry child" he demonstrated that he did not want to talk about it further by completely changing the subject to talk about a homeless man that was living outside the shops that were at the side of the house where he lived. He told me that he would go and speak to the homeless man, as he wants to see how he is. David seems touched by the fact that this stranger has no home to go to and he tells me how it makes him feel "sad". I wondered if David identified with the homeless man in some way and perhaps there was a connection in his sadness and the sadness of the situation that the man was in. I wondered if David was telling me the story to emphasise his feelings or whether this was the only way he could express himself, or even that whether talking to the homeless man was a source of help or an outlet for him. David was demonstrating his vulnerability but he did not state that he turned to anyone for help.

This was not the only occasion that David presented an authentic backstage presence. It was also highlighted on another visit when his brother Henry came running into the lounge semi naked after he had been playing in the paddling pool. As Henry ran into the lounge he jumped into his

mum's arms and she cradled, cuddled and kissed him. David did not like this and his facial expression changed to show he was not happy as he spoke up to his mum and pointed to say "Why are you holding him like a baby?" and his mum replied "we are just having a cuddle". For David this was too much because he perceived his brother to be already taking a lot of his mum's attention with his CF treatments and any additional attention he would rather have himself. In that moment he was demonstrating a jealousy of his brother and a want for attention from his mum himself.

David was not the only child to talk about having to tidy up their CF sibling's mess; Molly also mentioned this. Even though they do not want to tidy up, they do it anyway because it keeps the peace, but it also leads to internalized frustration as well as another expectation, another responsibility.

8.5 THEN AND NOW

For some of the protagonists within this study they talked about separate periods of time in relation to their experience with their journey with their sibling who has CF.

I noted within the data that Charlotte repeatedly talked about normal and in classifying normal she was making comparison between now, which is a time that she perceives to be normal, and a previous time when things were very different i.e. before her sister Emma was diagnosed with CF. Charlotte was seven years old when her sister was born and within a couple of months of her birth, she was diagnosed with the disease. In Charlotte's narratives it almost appeared as if it had been a defining moment in her own life, because she had experienced a different life before Emma was born. It was a life that was less complex in terms of family routine, there was no medication giving, no sister going to hospital or requiring treatment, there was no upheaval and mummy did not spend time at the hospital. For Charlotte when Emma was born with a diagnosis of CF this was an uncertain time, she did not really understand what was

going on and initially why her life and her family life had all had to change so quickly. When she refers to what life is like in her family she uses the words “It’s different because of Emma’s cystic fibrosis” and she later she adds “it’s quite easy to be me in our family, for me, because I am used to it now”.

In using the words “different” and “used to it now” there is an insinuation that there was a time when she was not used to things and the words represent a change and a transitional journey for Charlotte. She expresses that initially how when Emma was born she did not understand the condition of CF, let alone even know what it was because she was only seven years old and had not experienced it before. She gained a greater understanding over time about her sister’s condition once her mum explained things to her. This explanation made her feel much better. Talking about this triggered her earlier autobiographical memory of the uncertain time when life turned to chaos. She sought verification from her mum regarding the return of her memory of what she had witnessed.

8.5.1 SCENE 4(A): CHARLOTTE REMEMBERS EMMA’S SWEAT TEST

(Stage set Charlottes Lounge. Mum is sat in the dining area and her sister Molly and Emma are sat in the lounge with Charlotte).

Charlotte: I can’t remember what it was called. Mum what was it called when Emma was attached to that big long thing?

AH: Like a drip was it?

Charlotte: Yeah, like that.

Mum: It was her intravenous antibiotic.

Charlotte: Yeah and she was attached to that and Emma was like, we had to count the seconds or something and then we had to go to hospital for something. I can’t remember what it was, we had to measure the salt in her body and they put this thing around her arm and then like, I can’t remember but it came up with like a measurement and stuff.

AH. Do you know what they call that? It’s called a sweat test.

Charlotte: Oh

AH: So you are right, they measure the amount of salt in the sweat so that's really good that you remembered that, that's clever (Mum speaks in the background 'I can't believe you remembered that, you were seven then'.) This was a powerful reaction from Charlotte's mum.

AH: And you remember that from all that time ago

(Charlotte with her mum: Family visit 3. Interview 2)

In the narrative above Charlotte's autobiographical memory had captured the picture of an event that had happened when she was 7 years old. An event that was so significant she was able to recall some fine detail in relation to what she had witnessed happening to her sister. It was a picture that she had in her mind, but could not fully recall all of the words to describe everything that was happening in terms of her sister being unwell, so she asked for verification from her mum. However she was able to relay that she remembered they were measuring salt in Emma's body and she described how they put something around her sister's arm. Due to my background in children's nursing I was able to recognize that she was describing a diagnostic test.

Charlotte's mum was quite taken aback by her recall of this event, demonstrating the powerfulness of that time in their lives. Witnessing her sister having this investigation must have become embedded in her mind and would have caused some initial confusion and uncertainty as she mentioned earlier that she did not really understand at first what was going on until everything were explained to her. However she did not clarify what everything was. Charlotte was the only child in my study to make reference to events representing diagnosis of CF.

This time of diagnosis represented a time of chaos for Charlotte. There was a lot going on, with Emma having early symptoms of CF, and she was very unwell. This was the start of hospital visits, uncertainty in family life and general upheaval. It was just the beginning where an alteration in family life was about to take place as they would need to adapt to the complexities and challenges of accepting and living with a child with this disease. It was a defining moment between then and now, from old normal to new normal. To move from that time age 7 to now age 11, she would have experienced a period of transition, transformation and adaptation and this is evident in her own words when she states “I am used to it now”. It will have taken her some time to get to this point but she still acknowledges that life is “different because of Emma’s cystic fibrosis”. In a later comment from her mum at the end of one of my visits she also stated “Charlotte is used to it now”. In talking to Charlotte and hearing her story in her words, her tone of voice and facial expressions, I could not help but wonder if she had felt the loss of time before CF and whether she had gone through a grieving process for how things were to be able to reach the point where she is now which appears to be that of acceptance of the situation that she is in.

This differentiation of now and then in family life for the sibling is not just specific to Charlotte and Molly’s family, but can be a time of chaos for other families. A story of then and now is presented by Allie. In Allie’s guest appearance she is moved to centre stage by the dramaturge to read her email below.

8.5.2 SCENE 4 (B) ALLIE AGE 22 TALKING ABOUT WHAT IT WAS LIKE ‘THEN’

*“When my brother was first diagnosed with CF I was confused to why all of a sudden he would be doing daily physio and taking numerous tablets, I didn’t understand that this life changing chain of events were happening and we had no power to stop it. I remember making up daily packs of medicine with him when he initially started his course of antibiotics”.....
Allie continues ...*

"I have always been extremely close to my brother, he's my best friend, and therefore I was devastated and petrified of what lay ahead. Something, which stays in my mind as a memory of him being diagnosed, was been given leaflets and reading the statistics on life expectancy. It's a traumatic memory as it still makes me think of the future and that his life may not be as long as mine, this brings me to tears thinking about it".

(Allie: Email1)

Initially Allie talks about her confusion and lack of understanding in the sudden change of events in her life in a similar way to Charlotte. What comes across in Allie's quote is that everything was out of her control. She was powerless to do anything to change the situation that she was now in. The fine line of then and now was the recognition that a diagnosis of CF, something she had never heard of before had set the catalyst for life to change and it was never to be the same. What was different with Allie was that she was older than Charlotte when her brother was given his late diagnosis as he was 17 years old and she was 13, just outside the age bracket of this study. Her cognitive level of understanding was more advanced than Charlotte because for Allie at the then moment of diagnosis she was a teenager and when she was presented with information about the disease, it was too much for her. It was almost too much too soon, because the diagnosis was a shock and it turned her life upside down. She was mourning the loss of her brother that was, but now with a diagnosis of CF, a brother that would never be, due to being faced with this altered physiology. For some siblings they want more information about the disease as already stated, but for Allie it would appear that she was not in a state of readiness to receive the information that she was given and the timing was wrong. What she needed was some support. As a consequence Allie is still suffering the late effects of these earlier moments in her journey.

8.5.3 SCENE (4C) ALLIE TALKING ABOUT HOW THINGS ARE ‘NOW’

I find myself even to this day crying and saying why him, why him, but then he tells me he is one of the lucky ones because there are people worse off than him. I also find myself wondering why I escaped the disease, it is something I struggle with and constantly count my blessing for.

(Allie email 1)

What is different in Allie’s story is that several years on she is still questioning events, asking why and she appears to be expressing what could be referred to as ‘survivor guilt’ at having escaped the disease herself. Whereas Charlotte will say she is used to the new normal, Allie is clearly not and she needs help to come to terms with the journey that she is on alongside her brother. In emailing me with her story it was as if she was asking me for help. I listened to her story and I acknowledged her email content as well as advised of places where she could get help.

At that time she was provided with a leaflet about CF that outlined that the disease carried a reduced life expectancy, which she found very traumatic. Her brother was not diagnosed until very late at the age of 17.

Allie is now a 22-year-old student nurse who has chosen a career direction so as to help people who may be in a similar situation to her brother and her family. She comments within her email that her dad does not cope very well with her brother’s illness and he has found difficulty coming to terms with it. For Allie she feels the burden of her dad’s emotion and she wants to protect him. This was similar to the protagonists in this study. Even though she is out of the age bracket for the study, there was relevance in her words to demonstrate insight that not all siblings accept or fully adapt to the situation that they are faced with as she talks of her ongoing struggle, which she has taken into later life. Within my study it was not just the siblings that have to adapt in the then and now moments. It can also be the parents. In the discussion below Elinor was witness to her father talking about giving up work once they had two children with CF.

8.5.4 SCENE 4 (D) ELINOR'S DAD GIVES UP WORK

On my first family visit to see Elinor, the family invited me to stay for dinner because I had travelled a long distance and they knew that I intended to drive back home the same evening. I decided to take up their kind offer. It became apparent that Elinor's dad was a househusband who took on the key organiser/carer role within the family. In being invited for dinner I sat with the family around the table in their dining room that was next to their key stage set of the lounge. David, Elinor's dad was sat to my right and Elinor sat opposite me. Toby was to the left opposite his mum and Staci was opposite her dad. They informed me that they regularly had people around for dinner due to the nature of mum's work. I felt privileged to be invited into this family space and I felt relaxed with them. David was chatty and keen to share information with me and Elinor was witness to this information sharing as her father spoke of a then and now moment in relation to the consequences of having two children diagnosed with CF. For Elinor her performance was to stay quiet and to listen while her dad told his story. In listening, she was taking everything in, she did not dispute his story, she took it on board because he was talking about a then and now moment of family life that she had been part of. It was an important story and a significant one for her.

David stated *"I used to work as a fitness instructor but then one day we were all rushing around trying to do so many things/ treatments in the morning before going to work and I just crashed, I could not do it anymore it was just too much and I decided to give up work. If anything happens to either of the children someone needs to be home or if they need to go to hospital because Eaddie works away a lot. So now I make sure everything is organised at home."*

Within this dialogue David talks about a defining moment where he felt unable to cope any more as a parent due to living with three children, two of which have CF. As well as having a wife that needed to work away or travel around a lot. There was an age gap between Staci and Toby (both

with CF) of around 5 years so when they just had one child with CF it was easier to manage the treatments and daily family living but with two he found it too much. In stating that he just “crashed” was a period where he had what can only be described as an emotional break down.

As a consequence he knew that he had to make a decision to give up a career that he loved for his own sake as well as for the sake of his family. The ‘then’ moment was being able to do it all. Have the career and look after the children, do the daily treatments for the children whilst trying to juggle everything and cope. The ‘now’ moment is living a new life where he is at home as a fulltime dad and carer to his children and his wife. He completely manages the home, the treatments, the school run and he is available if any of the children are unwell with their CF or they need to go to hospital. For dad he felt that giving up his career was a loss of his masculinity as well as his aspirations. However he appears to have adapted to regain what had been a loss as a result of the transitions of living in a family with two children with CF.

This maintaining and reclaiming of masculinity was later expressed in Elinor’s discussions and performances of her and her sister getting ready to play football or when she was talking about going kick boxing, as these activities can be associated with masculinity and things boys normally do. Elinor discussed how David her dad had built her a Barbie dolls house; she provided an impression that stated in building the house her dad was demonstrating elements of his masculinity. Her own emulation of her father’s holding onto to masculine beliefs despite his change of role in engaging in what could be perceived in the traditional sense as feminine duties was also prevalent in her reenacting of the action man dolls that she was playing with on my first visit. This emulation of dad was also confirmed by Eaddie as she stated “The girls have action men not Ken (a doll associated with Barbie) he is not like a real man, David normally says if you want a real man have an action man he is more masculine”.

Losing his career as well as coping with CF was a major cataclysm, which was witnessed by Elinor. It has had an impact on her experience, development and socialization in the home as it was reflected in her performances. The reshaping of family life through this period of then and now had also redefined and influenced Elinor, as she emulated and supported her father's need to maintain masculinity whilst living in the context of CF. She has witnessed a delineation of his original role in traditional fatherhood to one of altered fatherhood where his career aspirations had to be put to one side as he engaged in his adjusted role within the family. This added to the complexity of her family life and highlights how then and now moments can be a difficult time for siblings that do not have CF. However; this is not always the case as presented by Erin when she talked more openly about her sister being commenced on a new medication called Kalydeco as she temporarily allows me back stage.

8.5.5 SCENE 4 (E) 'CHLOE'S NOW ON KALYDECO'

Descriptions of then and now for the sibling are not always related to deterioration of their brother or sister's condition, but can be for the better as was discussed by Erin. We were sat in the lounge and Erin was sat at the side of me on the settee initially very quiet just listening to her mum Sandra was talking to me about Chloe's new medication. Erin interjected into the conversation, as she wanted to explain that since her sister has been taking Kalydeco it has given her sister a new lease of life. She compares this time span of having a new medication to what it was like before as she states,

"Before (meaning kalydeco) Chloe was in an out of hospital for 2 weeks every three months" she continued " she would sleep all of the time and have fatigue".

This comparison of then and now was a recurrent theme in my visits with this family and it extended from my second visit to my third visit family visit where Erin expanded further in the scene below as she reminded me about the change in her sister.

8.5.6 SCENE 4 (F) CHLOE HAS IMPROVED

Stage set Erins Lounge

Erin *"She's got a tablet now called Kalydeco and that's helped loads, it's really good and she, it like helps her lungs and she like, they say for some people cystic fibrosis it feels like blocking your nose and breathing through a straw, you could see like the improvement even."*

AH: *You say it's like an improvement, in what way?*

Erin: *Like her breathing. Her breathing is much better, like she will have a normal life they say, they say she's got, it's like a new lease of life for her and it's just like really good.*

AH: *So you know before she had the, what you called the Kalydeco, yeah, the Kalydeco, what was it like then for you being with Chloe?*

Erin: *Like she still has to take the medication, she used to like cough, it didn't sound like a very good cough, it would be like a dry cough and just wouldn't sound very good. When she took this Kalydeco it's improved so much, you just, you just can't really.*

AH: *So what did you do when Chloe was coughing and not able to breathe properly?*

Erin: *Like she could breathe, it's just like it's not as we breathe, it's not as a normal person would breathe. She would take her medication, she would have the nebulisers as well and it's just since she had Kalydeco it's much better now.*

AH: *So you know a lot about cystic fibrosis, you're telling it well aren't you, yeah. Okay, so before the Kalydeco did Chloe go into hospital?*

Erin: *Yes, she still has to but it's, she doesn't go in as much, she hasn't been in hospital for a long, long time and normally she would go in for two weeks every two to three months. I didn't used to like it when she used to go into hospital but I knew she was in good hands because they would take care of her and that's all I used to think about.*

AH: *When you said you didn't used to like it, what was it you didn't used to like about it?*

Erin: *I just didn't like her being away from me, I just like it when I was with*

Chloe because we'd like be with the rabbits and we'd watch films in bed and we play games, I just love it, I love it when Chloe's here.

(Erin Family visit 3 interview 1)

Within this scene Erin provides detailed information relating to the 'then' moments with regards to her witnessing of sisters symptoms prior to her commencement of her new medication. The description presents a CF sibling who does not have a good quality of life due to the nature of her disease and the treatments she needs. This has also resulted in current admission to hospital that for Erin has meant spending time away from her sister who she loves so much. Such separation leads to anxiety and worry for Erin along with moments of isolation. Seeing her sister suffering and being aware of her quality of life when she was fatigued was also hard for her because it meant her sister could not spend time with her and it placed limitations on their relationship, but not on their bond.

For the 'now' moment Erin speaks with pleasure at how she can now sit wither sister and play with the rabbits that they both love. She has seen a difference in her reduction of daily symptoms as well as hospitalisation. This has brought a sense of relief for now for Erin and she is pleased with the change and pleased that her sister has commenced Kalydeco because it has enhanced her own experience of family life and the things that she is able to do. Chloe commenced medication 10 months ago at the time of my visit and during this period, the transition of then and now has been a positive one for Erin and her family. It has also brought other gains to Erin because it means if her sister is not in hospital, then, neither is her mum.

A concern about missing mummy was a key theme that was identified in the data analysis by the protagonists in this study and this will be discussed in the section below.

8.6 SCENE 5 (A) MOMENTS OF SEPARATION

Continuing on in Erin's discussion about her sister's previous repeated admissions she spoke of how if Chloe is in hospital for two weeks then her mum stays with her and she has to stay with her Nan. Even though she is happy staying with her Nan as she stated that her grandparents spoil her, she would prefer to be home with her mum. Erin was still trying to maintain a front stage performance in stating that she wants what is best for Chloe if her older sister is ill and realizes the reasons why her mum needs to be with her sister. However when I asked the question: "When your mummy is with Chloe do you miss your mum?" Erin responded "Yeah very much". There was an emphasis on the very much and as Erin spoke she looked at her mum.

The conversation continued back to Chloe's transition to adult cf services and in letting her front stage presence slip, Erin admitted that she was pleased that Chloe was going to the new hospital where her mum was not allowed to stay because it would mean that her mum would be home with her and that is what she wanted. Equally she still acknowledged that she wanted what was best for her sister and she would still miss being separated from her. Erin spoke with determination in letting me know that she would make sure that she still spoke to her sister everyday if she was admitted again to hospital. What she likes the best is when everyone is home together and they can watch movies and buy take away and play with the rabbits.

When everyone is together it makes Erin happy as she can feel the interconnectedness of a family bond that she treasures so much, rather than the fractured moments of when they are apart. Missing her mum is difficult for Erin and on the whole she tries to contain how she feels about this, but momentarily she was open and honest as she let her barriers down to expose a realistic self. Ironically for Erin in talking about missing mum and expressing how she was looking forward to a more positive future of having her mum around due to the transitional changes taking

place. Her mum informed me that she herself was going to have to go into hospital for a back operation. So for Erin, this will mean another adaptation and another stay at her Nan's while her mum is away. It is something else she will need to cope with but fortunately it is only in the short term.

8.6.1 SCENE 5 (B) MOLLY LOOKS UPSET

Another protagonist, Molly also expressed her emotion during my first visit in relation to her mum being away as she told me that her sister Emma "Was in hospital for 30 days once with mummy and I was upset and I did not see them much". As Molly blurted this out, somewhat unexpectedly, she paused as her body language changed. She drew her legs up onto the settee and almost curled up into herself a little, she folded her arms and legs. I wonder if she was thinking about that time and I could see that she looked upset and her eyes became watery. Her face all screwed up. She had previously been happy, chatty and lively, but this momentary shift in her demeanor was quite powerful/noticeable. In a later conversation with Amanda her mum raised the same issue of being in hospital with Emma, she herself acknowledged how difficult this time had been for Molly. Being separated from a parent is hard and it does cause emotional upset, separation anxiety, as well as a feeling of abandonment and being alone. It also means that mum is not there to offer help and support. For Molly it can be difficult because her mum is her mainstay, her constant, her security, and when she missing, it removes the safe sanctuary that she feels when her mum is present. Even though her dad stays at home to look after her if her sister is ill, it is not the same as having mum at home too. Missing mum is a loss and for some of the protagonists it is too much to have to cope with and can cause anxiety in other aspects of daily life, as I witnessed with David.

8.6.2 SCENE 5 (C) DAVID HOVERS BY THE WINDOW

During my second visit with David his mum informed me that she had broken her car key, so she could not get into her car. She mentioned that she was waiting for her father to come over to see if he could help her to

get into it. David sat next to me on the settee as he listened to his mum tell me about what had happened. During this visit David had been showing me how to make things with loom bands and he made me a loom band bracelet. The house was also a hub of activity that day with people coming and going in terms of neighbours and David's aunty and cousin. All of a sudden his mum looks out of the window and says, "Oh, pops here for my car, excuse me I need to sort this out" and with that she left the house.

Once she left, even though his aunty Ruby was present, David could not settle. He became restless and he sat in the place where he said his mum normally sits and as people walked past his front window he would call out their names and tell me who they were. His mum was gone for some time and he became agitated and fidgety to the point where she stood right in front of the window as if to look out for his mum, but she did not appear. As he stood there he was waiting, and watching and while he was pointing out whom other people were as they walked past his house, he was emulating his mother's behaviour, as he wanted her to come back home.

Initially I had wondered if he was bored or fed up with my visit but he said he was not. Once his mum returned he was much more settled as he went out to greet her at the front of the house. I could see that he became more relaxed. For David, his mum had only left the house to sort out her car it left him in an anxious and agitated state, which was a performance, witnessed by the dramaturge/researcher. He was missing her and wanted to be with her and to know that she was coming back. This was a backstage insight into what I can only describe as a display of separation anxiety because his mum had left the house. For David this made him feel insecure and his behaviour change was remarkable.

During my third and final visit for David he talked about when his brother Henry went into hospital. Initially when I asked "Who stays with Henry

when he has to go to hospital?" he responded by telling me that nobody stays with Henry and that he stays at the hospital on his own. David then admitted that he was not telling the truth and informed me his mum stays with Henry, and others look after him during his mother's absence. In this moment of not telling the truth I got the impression that what David initially told me was that he would have preferred to happen. That is for Henry to be in hospital alone, and for his mum to be home with him.

Nine out of the ten children in this study talked about their moments of mum not being present when their brother or sister needed to go into hospital due to their CF. Eight of the children exhibited periods of emotional upset to missing their mummy. Even Raff, who chose not to speak, pointed to a picture of a sad face when asked how he felt when his mummy was in hospital with either of his sisters. Where the protagonists have two siblings with CF, this can mean double the times where there is loss of mother being at home. This can be a difficult time for the sibling. Earlier on in the first scene the dialogue between Elinor, Toby and his mum, saw Toby who has CF specifically requesting for his mum to go with him when he has to go to hospital. Elinor did not question this as she was already in an emotional state of upset and being scared about her brother being ill. Instead she seemed to resign herself to the fact that it would be likely that mummy would go with Toby. However Eaddie (mum) did discuss that it may not be possible if she is working. This would mean dad would take the responsibility. If mum were working this would mean that neither parent would be available, which can add to it being a time of upheaval for the protagonist as they can be looked after by someone else. So not only are they away from their family, but in some cases it also means being away from their home.

Being away from mum also means being away from their sibling but for most of the children whilst they acknowledge that their sibling needs to go into hospital, they did not talk about missing their sibling (except for Erin), or their fathers'. Their primary concern was that they wanted their mum to

be at home with them because receiving their mother's time and attention is important to the protagonist. Their reliance and dependence on mum is their childhood need. Although experiencing these authentic moments discussed, it does not stop them from looking ahead to their own future.

8.7 FUTURE SELVES

Another focus within my research project was to explore how the protagonists see themselves and their lives in the future. I wanted to know what they hoped for in their imagined futures and the children were asked to think about this in preparation for my final visit. However some children wanted to talk about it before and one child addressed the issue on my first visit. Originally my idea had been that the children could create a second picture/ photo board to discuss the theme future selves. However what I found was that instead eight of the protagonists decided against doing a second picture and each of them said the same thing "Can we just talk?" Raff was the only child that drew a picture to represent his perception of future self. My research enabled the flexibility for the protagonist's choice and they were able to discuss their imagined future in our narrative interviews. I took the "Can we just talk?" as a sign that the siblings felt comfortable with me and they felt more readily able to express themselves. They were happy to talk but on the whole the discussions were short in most cases in terms of what they wanted to do in the future. There were some similarities and differences in relation to their perceived futures in relation to their choices as can be viewed below.

8.7.1 SCENE 6(A): CARING FUTURES AND /OR INDEPENDENT LIVES

Earlier in this act Allie talked about how she is a student nurse, as she wanted to help others like her brother. Both Charlotte and Erin had similar aspirations for their futures in working towards a caring career. For Charlotte she stated that she would like to be either a nurse, midwife or to work in a charity shop, but she also continued with the words:

“I just, I want to like help people get better and look after them, I’d like to look after children or elderly like in a care home or like when children are born in hospital and look after them. I would like to look after them when they’re sick, to go to hospital and know that you’re helping someone get better, like help, like make an impact on their life, like in a good way.”

Like Charlotte, Erin also stated that she would like to look after people with CF so that she could help them, just like the nurses who help her own sister. For both they wish to adopt caring roles that will allow them to assist others. They have witnessed what their siblings have been through in relation to CF treatments and going to hospital. They have also experienced their own emotional journey and this has been influential in their thoughts of their imagined future in extending their experience of their caring role at home a step further to move towards a career of helping others. They exhibit a realisation that caring is meaningful because it can have a positive impact on others and this is something that they strive for. Within their choice of imagined future they are expressing empathy towards others as well as realising they have a capability and responsibility towards caring. Such goals towards the future can be cathartic in a way of knowing they can help others, they can also help themselves come to terms with the situation that they are in and in doing so they can turn a situation around to do good. This is also synonymous with the previous chapter in relation to the importance of being good. What was also apparent in both of the protagonist’s narratives was the desire to stay close by to their own families.

For Elinor she eventually spoke of a future that was helping others in a different way, i.e. not in the healthcare environment but within a teaching role. She spoke of how she likes children and how she would specifically like to teach maths to primary school children. What transpired in Elinor’s discussion of future self was her uncertainty along with elements of not quite deciding her own future as she was very much pulled in different directions by her siblings. Her older sister with cf preferred her to move to

where she wants to live and for Elinor to work with her as a librarian. Whereas her younger brother who has CF, wants her to live with or near him and specified that she should have a husband who can cook so that would free her time so that she could help Toby to run a sweet shop that he wants. Both Elinor's siblings are demonstrating a need to have her nearby and they do not want to be alone. This places Eli in a dilemma for her future aspirations, as she feels torn between pleasing her siblings and meeting their expectations as well as considering her own. Her mum had suggested Elinor could be a teacher and she took this on board. However for Elinor her authentic words when not engulfed in a polarity were, "I am not posh, I do not want a fancy job in like an office or to be a fashion model and I don't want a car because I won't feel safe. I prefer a push bike". Elinor was largely undecided about her future but at times was resigned to the family suggestions and expectations of her at this moment in time. She is loyal to her family, they are her mainstay and they are important to her but she does at times feel like she has no control over her own world as she stated to me in a quiet whisper that I could barely hear "Nobody cares about my rules." This comment predominantly related to rules around sharing a bedroom with her older sister, but I could not help but wonder how it over spilled into other elements of her life as presented in the future-self situation. Elinor's caring included pleasing her family by presenting their thoughts over and above her own in order to maintain her positioning within the family as discussed in the earlier chapter. For Elinor it was difficult because she has two siblings with CF who both want her attention and she feels divided between the two.

8.7.2 SCENE 6 (B) SIBLINGS DISCUSS THEIR FUTURE-SELF

Some children did not feel fixed in such polarity and instead demonstrated a drive towards independence as David expressed wanting to join the army and expressed that "As soon as I am old enough, I am out of here". David loves his family and is particularly close to his mum, but his difficult relationship with his brother and his fear of cf continues as an opposing force in driving him towards independence and to a place where he can feel free from the environment that having a sibling with CF places him in.

This was similar for Raff who also strives towards independence as he presented in his picture that showed me that he wanted to own a sweet shop in a city away from his current home. He presented a tiny self who he identified as being him on his picture and he looked pleased with his drawing and with the idea of independence of owning his own shop. For Raff his picture was a positive expression of future imagined self. It was also away from CF and he was demonstrating making future decisions of what he wanted for himself as can be seen in his picture below. His future self is a sharp contrast from the earlier interaction with his sibling that was discussed in the first findings chapter.



Raff's 'future-self picture' Raff is the small figurine by walking towards the door.

Adam spoke of a similar drive for independence, which was with the support of his family in that when he wanted to grow up he wanted to become a footballer. For Molly, Nancy and Hattie their desire for independence is expressed with elements of fantasy and grandiosity. Nancy just wants to be a princess with super powers; Nancy wants to be a

dolphin trainer and care for dolphins having witnessed this on a recent memorable family holiday in Florida. Molly wants to live in a big mansion that has a swimming pool, a Jacuzzi and a maze. Molly expresses elements of caring in wanting to have children of her own, but also in wanting to babysit for others as well as train to be a dentist. For Molly her ideas for the future just free flowed as she slipped into an imaginary world that gave the researcher the impression that this enabled her to escape from her current reality of her emotionally presented concern of living with a sister with CF. It took away her worries for the now as it provided a positive imaginary future dream.

8.8 CONCLUSION

This chapter presents unique insights into the back stage parallel worlds of the protagonists as they journey alongside their brother and or sister with CF. The siblings have provided an insight into their worlds, where they have demonstrated their multiple presentations of self within their family. They have moved from more public self in front stage 'perfect/good' appearances to allowing a view of private self in their authentic performances. Presentations of then and now, discussions of moments of separation and in their desires for their imagined futures were also revealed.

Moving away from the front stage façade into a back stage presence revealed the contradiction, the disparity of their initial idealistic narratives, picture portraits/visual creations versus realistic worlds in which they live. Autobiographical accounts of their back stage lives exposed the complexity and chaos that they experience when living with a sibling with CF. Complexity and chaos that arises from altered disease trajectories, delineation of roles as well as childhood worries, emotional labour uncertainties all evoke an emotional response for the protagonist. This highlights their vulnerability in their daily lives, one that is not always visible to those who only see front stage performances because the

children are good at concealing and shielding themselves within their family and to the outside world.

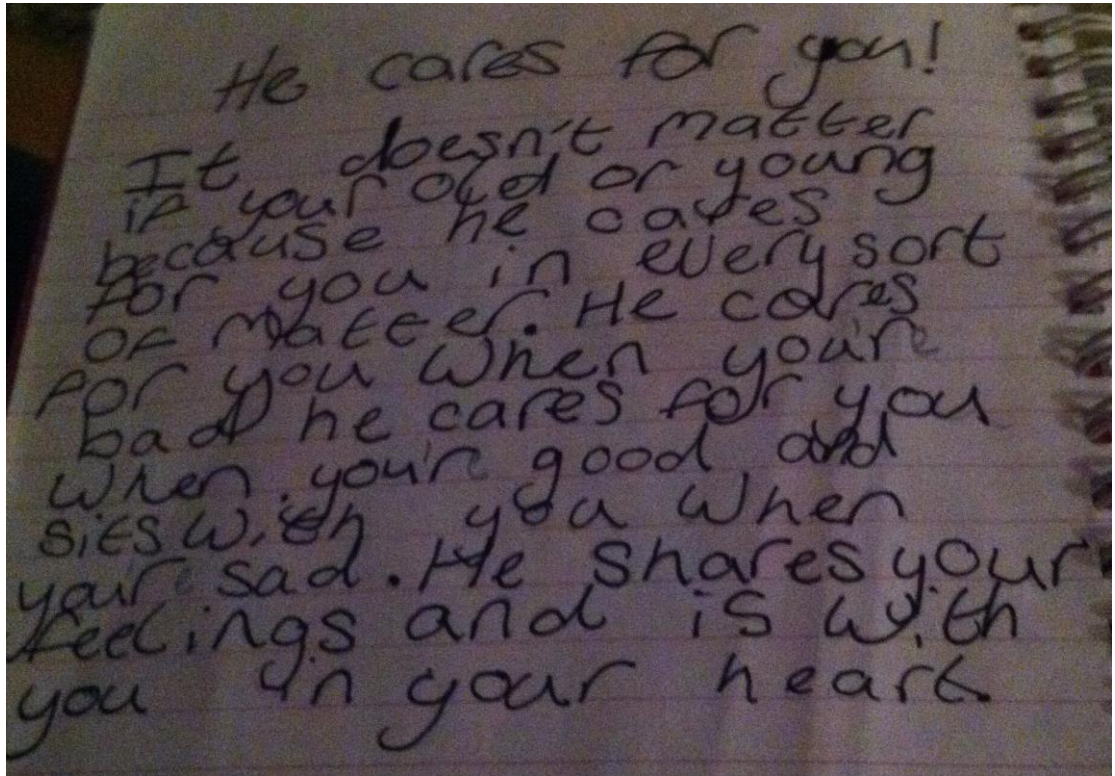
What this chapter highlights is the significant emotional labour and supportive roles that are encountered by the sibling living with a brother and or sister with cystic fibrosis. Such emotional labour takes its toll and it can impact on the health and well-being of the protagonist and is articulated through words such as “I am scared” or “I am an angry child” or it can be executed in the unspoken word with skilful conscious or unconscious performance when presenting self, back stage. Within the CF journey alongside their sibling the protagonists are listeners, observers and sometimes they are passive recipients of what is going on around them as they are unable to control the unpredictability of the disease and its impact on the rest of the family. For example if a parent is unable to cope or their sibling has to go into hospital unexpectedly they may simply have to cope.

Within this research study these siblings express a need for help as they face an increased burden and for some an additional responsibility. For some they are very resourceful in finding it in an external world away from the family i.e. with friends, at school, or by meeting myself as a researcher or through momentary distraction. Whereas other siblings they are not so able and they do not know where to turn and can be left in an anxious state like David hovering by the window.

The influential nature of living in a family with a child with CF is also presented in the protagonist’s discussions relating to their imagined future selves where they exhibit a want for caring and helping others and or the need for moments of independence. What is important in the future self is that on the whole they still remain loyal and please their family.

Living in a family with a sibling with CF can be a hidden journey for many protagonists if they do not expose the back stage world, but for the siblings in this study at least their world is no longer so hidden.

I have chosen to end this chapter with a poem that was written by Elinor:



“I wonder if I have been changed in the night. Let me think. Was I the same when I got up this morning? I almost think I can remember feeling a little different. But if I am not the same, the next question is “who in the world am I?” Ah, that’s the great puzzle.”

Alice in wonderland
Lewis Carroll

9. CHAPTER NINE: AFTER THE PLAY: DISCUSSION

9.1 INTRODUCTION

In reaching the discussion chapter as the reader you have come to the end of this production, one that has presented the disease of CF as an opposing force in the worlds of the protagonist siblings. CF has been shown to be a complex disease that can impact on the whole family who journey alongside the CF child's illness trajectory. It is a condition that requires a multitude of time consuming treatments due to altered physiology and the need for maintenance of multi-system health (Ward, Glass and Ford 2014, Barker et al. 2011, Williams et al. 2009, Mulroy et al. 2008, Foster et al. 2001, Hodson et al. 2007).

The dramaturgical lens has demonstrated how having a brother and/or sister with the condition can be influential in the daily experiences of siblings without the disease. It can impact on how non-CF siblings present themselves within their family, how they view their needs, how they put the needs of others first and how they are positioned in terms of social interaction alongside spatiality in family life. According to Rogers (2012) drama can provide an interconnectedness of the audience and the actors to enable commonality in engaging in and feeling the shared experience. With this in mind, in reaching this point of the thesis I wonder if the audience saw as I saw, I wonder if they felt what I felt and if they were moved as I was moved in engaging with siblings and their families. I guess I would only know the answers to these questions if reader and writer were to engage in a discussion about the behind the scenes preparations and the account presented.

At the end of any production there is always a discussion, a critique or commentary. Whether this informal as the audience leaves the theatre and talk to each other, or formally in a gathered discussion about the performance or in a published media synopsis and critique. For the purpose of this thesis, this chapter will present a coherent dialogue in which to engage the reader in a discursive commentary pertaining to the

core insights identified in the work. The discussion will begin with a reflexive narrative of my own experiential perspectives as a consequence of using dramaturgy as a framework in which to analyse the sibling experiences, and which enabled interpretation through the Three Act Play format (Goffman 1990).

Next the key research questions will then be revisited with answers provided within the text as the discussion focuses on the sibling portrait and the pieces of the sibling mosaic which include giving voice, the apocryphal self, sibling position and space and removing the mask. Siblings and their families will also add to the discourse as they present their experiential notion of being actors within this production. Sibling and family comments are presented here and not in the analysis section because they spoke after the event, at the end of the 'Acts', so it was their afterword and is their contribution to this discourse. Linkage will be made to previous research/theory in presented discussions. The chapter will also outline the implications/recommendations of the research for policy and practice as well as address the study limitations.

9.2 REFLEXIVE NARRATIVE: CHANGED PERSPECTIVES

Using the dramaturgic lens

It's early in the morning and as I turn over in my bed to face the window with my eyes partly open I can see that the room is dark, but I can also see the first glimmer of light peering through the gap in the curtain. My alarm has not gone off but I know it is time to get up as I can hear the dog get out of his bed. I know Miller my miniature schnauzer dog is stretching and shaking his body as I can hear the clink sound of his nametag moving on his collar. I know that he is going to move towards the child gate by the door in the kitchen where he sleeps. The child gate is locked as it prevents him from coming up the stairs in the night, but each morning when he awakens he always taps on the bars of the gate to let me know that he wants me to get up and give him his breakfast. So I step out of my

bed to go and tend to his needs, but as I stand up my thoughts are racing about my PhD, I suddenly reflect back to how things were just over four years ago when I started this journey. I think of the moments of uncertainty and my constant questioning of self as I wondered if my study protocol would be accepted, or if I would gain ethical approval and if I would recruit enough participants to conduct my research. In these very early stages of my journey I remained unsure of how I would proceed with my fieldwork, data analysis and work presentation. It was a time of exploration, a time where I would continually hear the words singing in my head “my sign is vital, my hands are cold and I am on my knees looking for the answers” (the lyrics of the song ‘human’ by the killers). The song reflected my literal sense of searching through the literature, doing my hand searches, looking for answers to so many questions as it was a time when I was looking for my analytical lens. I was searching for the framework for this study. During those moments if someone had told me that I would be presenting my work as a play, I would not have believed him or her.

Fast-forward to now and I realize that everything is different, everything has changed because I have got to this point and those earlier moments of uncertainty have gone and I am no longer “on my knees looking for those early answers” because I found them. I glance in the mirror before wandering down the stairs, on the face of it I guess I look like the same person, a little bit older maybe, but I glance again and I realize I am not the same person. I mean, how can I be? Having explored an aspect of the world through a new ‘lens’, that being dramaturgy, I realize that I have changed. I see things differently, I think differently and my world has completely altered as I notice things that perhaps I may not have noticed before - even in just everyday social interactions. I suppose it is a bit like what Donald Schon (1983) would refer to as an emergence from the ‘swampy low lands’ a place where I had been stuck and in my struggle to get out I saw things in very different ways leaving me with changed views

and perspectives. After such an expedition in this research things will never be the same for me.

Using dramaturgy as a lens in which to look at the world of siblings living with a brother and or sister with CF has given me new insight as can be seen from the work presented. I chose to share this insight in this way because the components of the framework in terms of exploring roles, stage sets, 'front stage', 'back stage' and 'centre stage' positions were congruent with that of a theatrical production. I considered it to be just so fitting. Particularly because during those early days of my field visits, I actually felt like I was watching and partaking in a play.

Following each field visit, as I left the children's worlds and wrote my copious amounts of field notes to encapsulate my observations, interactions, performances and the listened to narrative tales I could see their worlds reignite like the lighting of a flame that had momentarily been blown out by a whisper of a breeze. I would relive my own experiences of being witness, spectator and a researcher engaged in the temporality of family life. I was able to re visualize what I had already seen. Everything just felt so alive and I did not want to lose the realness of this experience by writing what I can only describe as "flat words on paper". I knew that if I did that then I would not do the siblings any justice in having their voices heard.

Presenting the dramaturgical production of three key 'Acts' has enabled me to present the siblings as 'live', because I wanted the opportunity to give the reader a meaningful account by providing a taste of the experience that I had when spending time with these families. This was important because the siblings are real children and they are the key participants of this work. They all had their differing ways of coping despite some commonalities, and they all had performances to give.

Choosing dramaturgy has enabled an engaging presentation and interpretation to be set without losing key aspects of voice. It has enabled the use of my own expression of creativity and enabled me to process and interpret information as a student with dyslexia. It allows the work to be imparted with expression and meaning in presenting the duality of the sibling and the researcher journey, which adds further to the uniqueness of the work. The dramaturgic play presented herein serves to enable engagement and interaction between the researcher and the researched, as well as between the writer and the reader.

Using dramaturgy as a framework allows a researcher to look beyond a front stage stance and to not take things at face value as it encourages one to look beyond what is seen. Presenting the siblings in a play has enabled them to have a positional movement away from a decentralized place, as they have been brought by the dramaturge to centre stage to perform their key acts that are representative of their world. It is a centre stage place that they were not used to, but they were made to feel special in taking the platform of this position in a dramaturgic framework (Murray 2000). In some ways I feel that dramaturgy chose me rather than me choosing it.

I have referenced others (Clarke 2014, Ward 2013) in my writing that have used Goffman's framework (1957/1990) in their qualitative studies, but I noticed they did not interpret its use to the limit of presenting the findings as a play. In some ways this demonstrates dramaturgical versatility in terms of it being executed in different ways in accordance with one's preferred research genre. It also highlights the differing interpretation in using this analytical lens. For this study my interpretation was situated through the play and this was made possible by the ten, sibling participants. Had I had a larger number of participants, such a choice may not have been made. Whilst I have changed perspectives and gained insight into the sibling worlds, I realize that dramaturgy is only one lens and there are other frameworks available also. However for me this is

how I see it at this moment in time, as presented in the aforementioned chapters with my interpretation of the worlds of siblings living with a brother or sister with CF. Since writing this PhD thesis, I realize I am not alone in presenting my work in such a way as I have discovered that Richardson (2015) also presented a play based upon his work after completion of his PhD exploring human geography with men of Irish descent. Richardson (2015) advocates for the theatre as a 'safe space' to share the narratives of participants.

9.3 RESEARCH QUESTIONS REVISITED

At the outset of this study the following research questions were proposed:

Primary question

1. What are the experiences of siblings within their family in the CF trajectory?

Secondary questions

2. How do siblings present themselves within their family?

3. What is the sibling perception of their wellbeing when living in the context of CF?

4. How does their experience influence the perception of their needs?

To enable the questions to be answered this participatory project was formulated to engage these children in narrative dialogue through participatory research methods. The protagonists could choose to create pictures/ collages or use photographs to prompt and elicit narrative discourse in relation to their storied lives. Flexibility and choice for the non-CF sibling was key to this study and as a result it enabled children to bring their own elements of creation to the work in relation their daily life experience of living with a brother and or sister with CF. This included their presentation of writings, toys, games and performances of music, singing and dance. I had no preconceived ideas of the sibling's selections.

This additional material enabled the protagonists to express themselves, in providing impressionistic and metaphorical performances (Goffman 1990). This added greater significance to the project in terms of sibling repertoire and presentation of self in relation to the theoretical underpinnings of dramaturgy being applied to this study (Goffman 1990). It was through these multi-modal methods and expressions when looking through the dramaturgic lens that a sibling portrait was formed.

9.4 AN OVERVIEW OF THE SIBLING PORTRAIT: A MULTIPLE MOSAIC OF SELF

The 'Three Act Play' demonstrates the multiple ways that the protagonists present themselves in their worlds, with their families when journeying along with a brother and or sister in predictable/unpredictable moments of the CF trajectory. This multiple presentation builds up to formulate a mosaic of sibling self. It is a self that is exhibited through the use of one's voice, through the use of one's silence, through the use of creativity as well as through the constructed and co-constructed performances.

Each segment of the mosaic captures the shifting moments that occurred when looking through the dramaturgic lens to observe elements of sibling front stage, back stage and decentralized positions. These elements are representations of the public and private self of the sibling and in how they want to be perceived in specific temporal moments. Moments of public self are situated in sibling ideology represented in some of the front stage stances of being perfect and being good.

Moments of private self are situated in their reality of momentary revelations, emotional releases and their narratives surrounding their multiple roles. Positional self in terms of their centrality within their family is represented in their interactions, re-enactments and spatial milieu. Piecing each segment of the mosaic together from the individual sibling scenes, acts and performed narratives create an overall portrait of the sibling representation of self.

The sibling portrait is not static as it is forever changing in the transitional turn of family life and the dramaturgical lens, just like that of the childhood kaleidoscope whereby with a shift of the lens the tiny segments of colour change to formulate a different pattern with a changed representation. One that remains still in the moment, until it is moved again, into another time or in another place or space.

Using the concept of portrait as a metaphor encapsulates each of the siblings lived mosaic moments to provide a snapshot, an insight and an invite into the previously unexplored lives of the ten protagonists in this study. The concept of portrait has been chosen as it draws on the work of Hermione Lee (2009). She suggests a portrait should come alive to represent life, characters, idiosyncrasy and personality, as the work should contain detail and stimulate the senses. The concept of portrait was effectively used in a previous healthcare research study to introduce a set of families living in the context of CF where the impact of the lifespan of the disease was explored (Bluebond-Langner 1991). Lee (2009) places portrait in opposition to that of an autopsy whereby this can provide a cold clinical representation of a soulless life, where voice is not heard and psyche cannot be explored because emotion and intelligence are not present. Therefore the metaphor and concept of portrait rather than autopsy was more symbolic to capture the mosaic of children's lives that are a collective representation of the portrait as a whole, a stance that is discussed further below.

9.5 MOSAIC SEGMENTS OF THE PORTRAIT

9.5.1 THE PERFORMANCE OF VOICE: THE VOICED SELF

It was advocated within the literature review chapter that siblings living with a child with a chronic illness needed to have their voice heard so that they could inform of their experiences to enable a greater understanding/insight into their needs (O'Brien 2009, Knecht 2015). The need to listen to and hear children's voices is also advocated with many policies including Sir Kennedy's policy review (2010), The Royal College of Paediatrics and

Child Health (2010) along with earlier policy documents, Doh (2008), Doh (2003). Providing a platform in this research study or perhaps I should say stage set for these children to perform “voice” within this work was consistent with this suggestion. It was also synonymous with the phenomenon of the being child as proposed by James et al. (2007) where the child can be responsible for their own construction in order to have an influence and say in their own being (Wartofsky 1981). Hughes and Ferguson (2004) suggest that this provides a new dimension to family life because this altered view of giving voice can provide diversity within the family as well as challenge traditional relationships.

Such diversity was evident within this study and in looking at the world of the sibling through the dramaturgic lens, the findings identified that the sibling voice presented of self was not always in the spoken word. The sibling voice was in their performance; it was in their non-voice, in a personification, in the silence, in the hidden, in the not shared as well as the spoken. Their voice performance was also in their observations, the self as a witness, as a spectator or passive recipient of the world around them. All of which were captured in their experience and presented here. Their voice was in the person they chose to advocate for them and in the distraction they chose to engage in such as playing on the computer (Adam), writing (Eli), singing (Erin), doing gymnastic cartwheels across their lounge stage set (Molly) and riding a scooter with precision along the road (Raff).

Their specific spoken vocalisations were sometimes directed, honest, and emotionally driven. However in some contexts their voice was an emulation of another such as a parent, or it was shielded, protective, imaginary or not quite true as words were spoken with falsification - such as with David in the previous chapter. On some occasions their voice was prompted or influenced to provide an image/impression to meet family expectations (Goffman 1990). Due to the interactive nature of their voice, they did not always perform alone.

9.5.2 THE VOICED SIBLING WITHIN THEIR TEAM

It was important to this study to explore the voiced sibling experience within what Jenkins (2003) would refer to as their collective as opposed to viewing these children in isolation in order to provide greater meaning in relation to their sibling selfhood. The term collective is used to categorise being with one's social group, such as in this case the child's family. It can represent kinship whereby through social interaction individuals transition and develop as a result of their engagement with one another (Mead 1934, Cooley 1964, Jenkins 2003). A preferred term used by Goffman (1990 p83) in his discussions of presentation of self, was that of "team" and this will be explored further in this discussion. Such transition within a collective or team is an ongoing rather than a static process as was captured in the findings chapters of this work through the exploration of the front-stage, back-stage and centre-stage/decentralised presentations/positions.

It was through these constructed and co-constructed performances that the siblings were able to communicate their idealisations of their world in offering their front stage stances. Their performed voice enabled them to express their decentralised positional status within their family alongside their socialisation and influence moving them out of the way and towards off stage place sets. The siblings performed voice to communicate their multiple roles and transformations which included being a good sibling, being selfless in putting their CF siblings needs first and not really considering their own requirements. In being unassuming in not wanting to draw attention to themselves so as to avoid being in the limelight. They also communicated their policing role.

In looking through the dramaturgic lens I witnessed the siblings move towards a trust of the researcher/the dramaturge where they opened up in their communicative performance to tell of their back-stage worlds. It was here where they performed a voice of private self to reveal their

authenticity. The non-CF siblings shared their inner most feelings that related to experiences of family life and living with a sibling on the CF trajectory. They articulated their feelings, worries and concerns through various means and they were able to make comparisons of then and now moments as they identified and compared timescapes in their parallel experience of moving along the CF disease trajectory with their brother and/or sister.

The sibling performances of voice were skilful because their interactive diplomacy required thought, tact and wisdom in order to keep the peace, avoid negativity or upsetting the equilibrium of their family life that could be detrimental to sibling self and/or their family (Goffman 1990). Such performativity was staged within the place set of each of the children's family home and in the context of family life that was important to each child, as this was a place of familiarity and security of their daily milieu.

The sibling voiced performance informatively represented their dialogic self that was relevant to the cultural social interaction in the positioning of self and other (Hermans 2001). It was insightful in relation to their presentation of self in their worlds. I am in agreement with the literature that advocates for the children's voice to be heard (O'brien 2009, Knecht 2015, Sir Kennedy's policy review (2010) The Royal College of Paediatrics and Child Health (2010), Doh (2008), Doh (2003) and with Prout's (2007) reference to the recognition of the 'being child'. However, I suggest that there is need for greater emphasis on providing opportunities for children to have their voices heard, as well as a need for more attention to be paid to what is actually meant by voice, what it entails and how voice may be best presented by children. Assumptions can be made that voice is only in the spoken word, but as this study has demonstrated, voice as a way of self-expression, can be seen in the child's performance actions as opposed to verbal clarification alone. This has implications for practice and policy because to gain greater understanding of children's worlds

more emphasis needs to be placed on taking note of their whole co-constructed performance as a voice along with their situational context.

9.5.3 THE APOCRYPHAL SELF: FRONT STAGE PERFORMANCE

The term apocryphal can be used to represent “doubtful authenticity” (Oxford dictionary 2015). Much of the literature pertaining to apocryphal lives is seen in theological texts as opposed to healthcare or social science (Metzer 1957, Ellis 1992, McDonald 2009, Davis 2013). The concept was also presented by Morgan (2015) in her discussion relating to the consequences for a family member who sat the eleven plus exam in a past generation.

However I wanted to use this term to represent the discussion of the ‘non authentic world’ of the protagonist that has been presented in their front-stage stances within this study.

In looking through the dramaturgic lens non-CF siblings have presented front stage performances of idealised selves in relation to being a good brother, sister, daughter, son and they chose to give an impression of good self. These findings extend the work of Rowe (2007) because non-CF siblings are explored in a specific chronic illness trajectory, which is different from her discussions in terms of a family situation in the context where brothers and sisters are healthy. Also Rowe’s (2007) focus is from a psychological perspective as opposed to social interaction and presentation of self.

Whilst Rowe (2007) suggests a motivating factor in that siblings like to be seen as being good because it puts them in a favourable light with the reward of positive parent attention, as they will be seen as worthy of being cared for by exhibiting good behaviour. What this study contributes is that even when non-CF siblings are not receiving parental attention and the focus is not on them, they still present with ‘good’ behaviours. This was evident in families where a child had either one or two siblings with CF.

The motivation for exhibiting such behaviour would appear to reach beyond the need for positive parental attention, as their motivation can be to ensure family stability by maintaining equilibrium in the context of their world where they have a sibling with CF. Contrary to Rowe (2007) who suggests that siblings can compete to be bad, this study did not witness such competing behaviour as non-CF siblings demonstrated a passive acceptance of their contextual situation and they did not rebel. They also demonstrated wisdom beyond their years, because they were skilful in their interactions and containments, such as how they recognised the context of their cultural familial milieu in the illness trajectory. Importantly they understood that their sibling with CF had to take priority due to their daily treatments that were needed.

The protagonist performances of good behaviour were highlighted in the findings chapters of the work, for example when the sibling Adam set up his stage set and read a story to his brother from a book that he had bought him out of his spending money. Or when Molly chose to be a playmate to her sister Emma when really she had preferred not to. It was demonstrated when Erin used positive language and when she would look at her mum for cues to make sure she was not speaking out of turn in anyway as well as when she wore her perfect pretty dress. It was also heard in Charlotte's words of "everything is okay" and the pleasing of her mum. Giving the impression of being good and everything being perfect, represented an ideal self that also then extended to living a perfect family life, as was viewed in Charlotte's perfect picture. In the front stage the protagonists were giving the impression of an idealised life by highlighting perfect moments, moments of escapism like Molly's family picture or by being cautious in their vocalisations, performances and creations.

According to Berns (2013) their front stage performativity or 'histoire' of idealisation of perfect can be an imagined performance that is reformulated in the protagonist's head to give an illusion of what they believe, and what they want to believe, about their experience. This

extends and supports the work of Goffman (1990) as it relates to his work on impression management where he discusses that social actors aim to give an impression that they want to give or that they believe the dramaturge may want to see. It also supports the work of Markus and Nurius (1986) who discuss the presentation of goals and incentives within idealisations of possible selves to depict what a person would like life to be like. Such representation was also relevant in their depictions of sibling future selves where they provided narratives of how they saw elements of their future, which included a strive towards independence for some, being near their families for others as well moving towards caring job roles.

9.5.4 AN APOCRYPHAL SELF: PROTECTING SELF/ PROTECTING THE TEAM

Providing a good impression in relation to self and family life to depict idealisation is congruent with the work of Goffman (1990) where he discussed presentation of self in everyday life in relation to the performance of an individual who is part of a team.

I have previously suggested that in this study the team is the family and the individual is the protagonist. Goffman (1990) proposed a framework consisting of three elements pertaining to performing within one's own team and suggested that to be within a team and to be accepted within that team, an individual had to perform within the rules of the accepted team framework. The three key dramaturgic perspectives put forward are loyalty, discipline and circumspection.

9.5.5 LOYALTY

In relation to loyalty, he suggests that team members must act as if they have accepted certain moral obligations within their group because individuals must not give secrets away or betray its members. They must provide a convincing performance to the audience. Rowe (2007) also recognises the importance of loyalty in relation to belonging to a social unit such as a family.

9.5.6 DISCIPLINE

In relation to dramaturgic discipline Goffman (1990) suggests this involves demonstrating the emotional intelligence to not to get carried away with one's own show. In being disciplined one is reserved, has discretion in seeking to avoid any faux pas as well as conceal anything they deem to be unsuitable.

9.5.7 CIRCUMSPECTION

Lastly he talks of dramaturgic circumspection whereby members of the team prepare for possibilities in advance for their performance so as to not be caught unawares. Such preparation includes finding out how much loyalty and discipline is needed to support the team.

9.5.8 LINKING THE THREE KEY DRAMATURGIC PERSPECTIVES TO THIS STUDY

In relation to this study in considering these three dramaturgic perspectives: all of the protagonists were loyal to their families in their front stage performances. Miller et al. (1984) suggest that such loyalty can occur within a collective regardless of the relationship between individual members. Non-CF siblings in this study provided convincing acts and upheld the moral family code in relation to expected values and beliefs. Their performances were convincing to their audience, and to their team as well as the dramaturge. Their words were protecting and shielding so as not to betray their family or have consequences for self. Where a faux pas was made, for example when Erin's mum Sandra mentioned that her daughter had omitted to place the medication kalydeco in her picture, Erin subtly smoothed things over by taking cues from her mum to stay in line with her in the conversation rather than maintain her own stance within the performance. As a consequence Erin suddenly remembered what she had stated she had forgotten to place on her picture.

Goffman (1967 p3) extends his discussion relating to interaction face work and suggests that it is important to maintain what he calls a line to save face in a social encounter. Within this situation Erin was face saving for herself and for her mum. This was a protective encounter because she

did not want to upset her mum and she did not want me as the dramaturge/researcher or her mum to view her unfavourably. Goffman (1967 p15) would refer to this as a “corrective interchange” where the offender is given an opportunity to “re-establish the expressive order”.

Throughout my study the strong protective bonds that the siblings had with their family were powerful and congruent with Bank and Kahn’s (1982) view of the sibling bond. Goffman (1967/1990) would suggest such protection and loyalty in relation to the team framework is a defensive behaviour that serves to protect the individual from being alienated from social interaction and from their social group. Hollway and Jefferson (2000) also recognised such tact within their work on free association narrative interviews where they also present those being researched as defended subjects. However unlike Goffman (1990) their work relates more to psychoanalytical theory.

A unique contribution of this study is that the findings extend the work of Hollway and Jefferson (2000) in relation to their view of the defended subject. Whilst the focus of their work relates to the fear of crime, this research has highlighted a similar defence, which is demonstrated in the multiple roles that child siblings present in order to be perceived as being good in the context of family life within the disease trajectory. This is not a study of a fear of crime, but the children may be fearful of not showing loyalty within their social group as they do not want to upset the family equilibrium and therefore maintain being good in a front stage stance. Klein (1988a; 1988b) would suggest such a defence mechanism to be based on one’s prior experience and suggests such behaviour can occur due to fear of anxiety. Klein (1988a: 1988b) adds that fear of anxiety is something that is learnt from birth, as an individual learns to differentiate between what is good and what is bad and how this evokes feelings of contentment or unrest. Rowe (2007) recognises siblings defence in her writings to be, a way of protecting oneself as a person, but also like Klein

(1988a; 1988b), Rowe (2007pxi) recognises such defence to be due to fear of annihilation.

Hence, this work extends Hollway and Jefferson's (2000) theory of the defended subject within their social interactions, because children have also presented themselves as defended subjects within their family when living in the context of CF. The use of a dramaturgical lens to explore sibling experiences provides a congruent link between a front stage presentation and a defended position in terms of loyalty, circumspection and discipline.

The siblings in this study in the front stage performance are providing an impression of a desired life, perhaps a preferred life where everything is perfect without the opposing force of CF. However it is a life not lived, it is an apocryphal life (Morgan 2015), as it is delineated from the reality of the context of their family situation in living with a brother and or sister with CF as was demonstrated in their contradictory back stage performances. Their idealisations could also be representative of a lost life that they may be grieving for in terms of their experience of an altered childhood journey as a consequence of CF, particularly if they are an older sibling and remember a part of their childhood before the disease entered their lives or as a younger sibling wondering what life could have been like without the condition. Charmaz (1983) recognises this loss of self in relation to children with chronic illness in terms of their own limited quality of life, isolation and burden to others.

I would argue a further consequence of this study that has been demonstrated is that the children's experience within the CF trajectory can be 'turned on its head'. I would argue that it could also be applied to the sibling of the chronically ill child as they too encounter an altered lifestyle with moments of isolation and they can be the ones that are burdened within their family, particularly if they are a child who has more than one

sibling with CF. For both the child and the sibling, therefore they are each journeying on a life lost, as well as the one they are living.

With such a front stage stance these children become containers of their own and their family's emotion and feelings; especially in relation to their experiences encountered. Such containment can be burdensome, as it requires skill and diplomacy to maintain their line within their family. Although in doing so, they remain loyal and protective to self and others. James et al. (2007) would suggest the front stage skills presented with the stance of tact and diplomacy is part of the being child's interactive transitional journey in seeking identity as it is where they learn to distinguish between their sustainment of self and not self. In doing so, they learn about social interaction and the importance of order through their own reflexivity.

It is therefore important to not always view the non-CF sibling's presentation of their good behaviour to be a true representation of self, because it may be a concealment of their emotional status and a way of protecting the self, their family and maintaining their positional status so as not to upset the equilibrium of their world.

The identification of the concealment and containment of emotion of the non-CF sibling provides a unique contribution as it extends the work of Hamama (2008) in terms of burden that siblings may encounter in an illness trajectory. Non-CF siblings in this study do contain and conceal their own as well as their family members emotions - a task that is burdensome. This is different to Hamama's (2008) discussion, where burden is highlighted in terms of sibling role overload due to care giving activities that may be expected of them and of the emotional burden that may be experienced because of negative feelings they may feel towards their chronically ill sibling if they have to care for them. This study contributes non-CF sibling containment and concealment of emotion along with presenting oneself as being good to protect oneself and the family

unit as an additional burden, specifically in the CF trajectory. This study presents this burden as greater where a child has two siblings with CF.

Whilst this protective nature of the sibling is congruent with the earlier findings of the CF family study that was carried out in the 1980's by Bluebond-Langner (1991; 1996), her work can now be considered outdated because there have been major progressions and changes in the disease trajectory since the 1980's. CF remains a lifelimiting illness but there is now recognition of specific genotypes that influence the disease progression and presentation. There have also been advances in treatments available as well as advances in life expectancy so the disease is no longer recognised as a childhood disease because CF patients live beyond the childhood years.

In the 1980's the median age of life expectancy was 19 years of age with many patients not surviving beyond childhood. In the present day the median life expectancy is 41 years of age. Due to the longer life expectancy there are now additional presentations within the illness trajectory such as CF related diabetes. This can present different challenges for siblings and their families.

This study provides a unique contribution as it sheds a new light in terms of how the changed disease trajectory has altered the dynamics of family life. This contribution updates the work of Bluebond-Langner (1991:1996) because it provides new insights into family interaction, positional spaces and demonstrates a shift that has occurred in the sibling role. Non-CF siblings have moved away from being primarily helpers in terms of treatment giving to presenting themselves in a multitude of roles so as to be viewed as being a good sibling. As mentioned previously being good presents a front stage stance of containment, where siblings are loyal and protective of oneself and their family is in order to maintain a sense of equilibrium. It also demonstrates that the family are essentially a team managing the CF trajectory and it is important that each team member

understands their role, position, place and space so that the family is ordered and able to function. Non-CF siblings demonstrate an acceptance and understanding of their role within their family and they work hard as a member of the team to ensure stability is maintained because they have the wisdom to know it could be detrimental to the family functioning if they were disloyal.

9.6 SIBLING POSITION AND SPACE: POSITIONAL SELF

Similar to earlier studies focusing on siblings living with a child with a chronic illness (Sloper 2000, Murray 2000, Sharp and Rossiter 2002, Van Riper 2003, Wilkins and Woodgate 2007, Bellin and Kovacs 2006, O'Brien 2009, Knecht 2015) and specifically CF (Bluebond-Langner 1996), this study identifies moments when the non-CF siblings received limited attention and focus. These moments occurred during treatment times when their brother and or sister required medication or physiotherapy. They occurred at mealtimes where the focus was on the CF child's nutritional maintenance with need for digestive enzymes as well as other times of heightened vigilance if the CF child's symptoms worsened. Siblings were also separated from a parent when the child with CF was admitted to hospital or when the child required clinic visits. In these moments where the focus was on their chronically ill brother and or sister, this study identified that the protagonists felt different, felt left out and what this study also identified was that when there were two siblings in the family with CF, then the limited attention was noted even more and the non-CF child felt like they were the odd one out as they compared themselves in terms of self and other (Hermans 2001).

This study also identifies how this differential focus of attention and treatment influences the sibling positional status within the family, similar to the findings by Bluebond Langner (1996). However contrary to the work of Bluebond Langner (1996) who noted the acting out behaviours of non-CF siblings as they rivalled for parental attention at treatment times, this

study has demonstrated that the siblings did not act out at these times, instead they demonstrated wisdom in the when and how of being good as mentioned above. This is also congruent with Rowe (2007) as discussed in the section above of the apocryphal self. Where siblings have tried to gain a moment of attention just generally whilst a parent is focused on a treatment with the child with CF, for example in asking a question or wanting to speak to their parent, it has been demonstrated that they are socialised to be good and be out of the way. This was demonstrated when Eadie gestures and vocalises “Not now Eli” to her non-CF daughter. Wisdom and realisation for the sibling are gained from these moments, which in turn further influences their positioning and spatial status.

9.6.1 IDENTIFYING RELEVANT POSITIONAL SPACE

Tuan (2001) recognises the importance of place and space in childhood and discusses how children view place and space in the moment and in relation to activity. What is unique about this study is that in relation to the above similarities with the other studies listed, it additionally highlights how the emotional positioning in terms of limited attention and focus of the sibling, influences their physical position and use of space within their home, which is their key stage set. This study has identified that there are three spatial positions that siblings occupy within their home as a consequence of living with a brother and or sister with CF. The three positions “in the wings”, “left of centre”, and “off stage” place sets are all decentralised spaces/positions that the siblings are socialised into through their co-constructed family interactions that occur during moments in the cystic fibrosis trajectory.

9.6.2 POSITIONAL SPACE ONE

The position of “waiting in the wings” presents the sibling with a reserved demeanour, holding a quiet stance, not drawing attention to themselves, sometimes in a space of hiding or not fully in view as they await permission or a glance of approval to come forward to take a front stage position. Siblings waiting in the wings exhibit such behaviours because

they are not used to being central or the focus of attention when they have visitors because they do not have CF. It was a position that I noticed in eight of the ten siblings in the study on my initial visits and it was a sharp contrast to the up-front greeting received by the children with CF with their questions and comments of “Are you here to see me?” Being in a position of “waiting in the wings” and waiting for the approval or gesture to come forward was normal for the protagonist because they were used to having regular visits from members of the CF teams so they knew where to position themselves in being quiet and reserved and this was evident in their presented performance and narrative.

9.6.3 POSITIONAL SPACE TWO

The position of “left of centre” is stated to represent one of the positions that the protagonist sibling takes when their brother and/or sister is having their CF treatments. It is a position where they are in the same room as their CF sibling and can be classed as observers, witnesses, spectators or passive recipients of the family show or their siblings show because they are not actively engaged in the treatment giving process. As onlookers on the side-line they watch and experience what is going on but have no control over the events because the CF treatment has to take priority in order to maintain their sibling’s health. Left of centre moments can occur when medication is being given, at mealtimes and when physiotherapy is taking place.

9.6.4 POSITIONAL SPACE THREE

The third position is where the protagonist sibling occupies an “Off stage” place set in the family home away from family members including their CF sibling. It is a place and position where they spend time alone occupying one self while their brother/sister is having their CF treatment or when being visited by a member of the CF team. The key off-stage place was the children’s bedroom, a place of distraction that was free from any CF treatments or medications. It can be classed, as a safe space for the sibling to go as they can be shielded from procedures that they do not want to watch or family members does not want them to see. This space

is made to look special due to its situated toys technologies, artefacts and favourite things which are presented for the children to entertain themselves in solitary play and re-enactments such as Eli with her Barbie room - or to engage with others such as Adam who although alone in his room, could play his football game remotely with a friend.

For some of the younger children in the study this place set was not one of preference but one they were asked to go. For others they went of their own accord and were socialised into going off stage because they had the wisdom to know it was not their time for attention and the focus was on their sibling with CF.

These three key positional spaces discussed where siblings are waiting for their moment, or on the sideline, or alone and not the focus of attention are representative of the non-CF sibling as being in a decentralised position. It is not a hidden position, but a necessary one in family life because of the opposing force of the disease of CF along with its necessary treatment requirements. Being aware of these positions/spaces brings new insight into the experienced world of the sibling living with a brother and or sister with CF and adds to the earlier discussions in chapter 2 relating to the childhood space of home (Buckingham 2000, Edwards et al. 2005, Lee 2001). It also highlights sibling adaptation in family life as well as their creativity and resourcefulness in using their time in their off stage place sets.

Identification of the three different spatial interactive positions that are discussed above provide a unique contribution in this work because it challenges and extends the work of Goffman (1959), as his primary focus relates to front stage and back stage positioning as well as centre stage. However, what Goffman (1959) does not explore are the different positional places between front stage, back stage and centre stage. Buss and Briggs (1984) suggests that the dramaturgical model presented by Goffman (1959) assumes a role presence at all times and that there is a

fluctuation between the positions of front stage, back stage and centre stage.

In highlighting and exploring the positional spaces of being in the wings, left of centre and off stage, it adds a new dimension in the understanding of positioning within social interaction particularly in relation to family life. It also enables the reasons for the changed positional dynamics in the context of CF to be highlighted.

As a consequence of the discussion surrounding positional spaces, the decentralised positions and being good that have been identified in this study, what has become evident is that siblings living in the context of CF are actually silently central. This is because it is through their strategic movements, positional use of space, interactions, roles of being good and containments of their own and family emotions that non-CF siblings can be identified as a key member of the team, because through their skilled performances it is they who enable family stability to be maintained. This also adds a new perspective with regards to siblings feeling left out or viewing themselves to be the odd one out because non-CF children may not recognise their centrality in being a key member of the family team.

9.7 “REMOVING THE MASK”: EMOTIONAL SELF / ROLE AND BURDEN

This study provides novel insights specifically in relation to siblings living with a brother and or sister with CF. In terms of highlighting elements of negative psychosocial wellbeing, the findings are consistent with the literature relating to siblings with the chronic illnesses (Murray (2000), Sloper (2000), Alderfer et al. (2010), Sharp and Rossiter (2002), Hollidge (2001), Wilkins and Woodgate (2007), O'brien (2007), Knecht (2015)). What this study also adds in demonstrating the findings are a greater focus on the sibling performed voice as opposed to that of another.

The work presents the type of emotional labour that siblings experienced and it was discussed that only in their 'back stage' narratives where they removed their shielded masks of idealisation, that it was possible to reveal a contradiction of authenticity. It highlights some chaotic and complex moments that they experience as they move along a parallel journey with their CF sibling on the altered disease trajectory, which is synonymous with the aforementioned altered childhood journey. Siblings provided accounts where complications were encountered with their brothers and or sisters with CF and where changes in treatment were necessary (such as when their mothers were required to spend time in hospital with their sick sibling) which meant times of separation for them. They also provided accounts relating to a time when their sibling was diagnosed with CF and when new medication was introduced to their CF-siblings regimen. These accounts were provided in moments of comparison in relation to timescapes of then and now

Within their narrative performances the protagonists vocalised a range of emotions in stating "I am scared" or "I am an angry child" or they did not vocalise at all as they chose to communicate with silence. They acted out their anxiety; they expressed their feelings including fear, sadness, apprehension, uncertainty and frustration. They demonstrated visible emotional upset in relation to their experience of living with a brother and or sister with CF particularly in relation to diagnosis and/or deterioration in their sibling's condition, along with missing their mum in those moments of separation. Witnessing/experiencing parental stress and worry was noticeable within the study as well as sibling adaptation to changed parental roles

Within their interactive family performances some of the protagonists also demonstrated that they were subject to the resentment and bullying from their CF sibling as they were told "you haven't got it" meaning the disease. There were also instances of scapegoating where the non-CF child would

be blamed for doing things they had not done by their brother and or sister and they were made to clean up a mess that they had not made.

Siblings expressed worries about their sister/brothers condition because as Molly says "Some people die of that" and they expressed a need to know more about the disease. Siblings also demonstrated their knowledge of the condition in re-enacting treatments and doing the "pat pats" of physiotherapy and stating the names of medication and what they do. Siblings were also aware of and recognised a changed body image of their brother/sister because of the portacath that they had inserted and what it was like when they had intravenous antibiotics or from scars of surgical intervention. (The photographer Ian Pettigrew (2015) in the Canadian book "salty girls" presents such images, where young girls with CF expose their altered body image). They were witnesses to their CF siblings' upsets as well as their parental worries about the CF sibling and for some they had encountered the moment that family life changed as a result of their parents separating. They also had to transition and adapt to changing parenting roles along with parental absence as a consequence of the priority needs of CF.

Goffman (1990 p115) would agree that the sibling performances of authenticity in terms of revealing their emotions are a matter of contradiction in comparison to the previous idealisations. A contradictory presentation of self was also recognised in the research conducted by Ward (2013) in relation to his exploration of a population of "Valley Boys". Goffman (1990) suggests that it is in these backstage performances that an actor can relax or change their behaviour in the removal of a front stage mask, which delineates from the prior front stage character. He also states "the back region is a place where the performer can reliably expect that no member of the audience will intrude" (Goffman 1990 p116). It is a place of secrecy which can be kept hidden, but is also takes skill for the actor to carefully remain in control as they fluctuate between the front stage and back stage regions as they attempt to cushion themselves from

established demands and expectations that are placed on them. He suggests that there is a correlation between the behaved performance and the region of front and back stage. Such alternated behaved performance was notable in this study and it links with Mitchell and Zieglers (2013) view of the child understanding one's own mind as well as that of others.

Similar to the work of Novak and Guests (1989), Blue-bond Langner (1996) and Hamama (2008) this study also identifies that siblings take on multiple roles when they are living with a brother and or sister with cystic fibrosis. Specifically in relation to the work presented, these roles include helping, policing/surveillance, playmate, peace keeping and protecting.

This study demonstrates that siblings are not primarily helpers in terms of treatment giving activities in the home, because only one sibling who was the oldest in the study mentioned helping in terms of getting their younger sisters medication ready and this was only sometimes, so as to help her mum. The other siblings all moved to the aforementioned positional place/space sets during treatment giving times. However helping behaviours included being a playmate and entertaining their CF sibling and part of this included activities such as going on the trampoline which was an indirect way of encouraging active breathing for the CF child and was seen as part of their physiotherapy. Sometimes the protagonists took on this role despite not wanting to, mainly because they knew it was expected of them.

Siblings were also expected to look out for their sibling if they were in the same school and particularly for one sibling she was given the responsibility of policing her twin sisters eating habits/nutritional intake along with ensuring that she took her own Creon. She was then required to report back to her parents to provide a check in report of her sister's activities. Her role of policing and surveillance increased as her sister then developed CF related diabetes. Another sibling also had to increase her surveillance of her brother in school because of his

complication of oesophageal varices. These additional roles of policing and surveillance added a burden to the non-CF siblings during their school day (Hamama 2008, French and Caplan 1973). It also meant they had the added responsibility in needing to recognise the signs of their CF siblings deteriorating symptoms and to know who to go to for help. However, their reward was positive attention for being good (The importance of this being stated earlier). Siblings in this work were also seen as peacekeepers and protectors in their family performances, which meant behaving in ways so as not to upset or antagonise their CF sibling or their parent. They seemed to have the wisdom and maturity to know that this was important in order to maintain family equilibrium as they had developed empathic understanding of the impact and burden of CF on the family as a whole.

As a consequence of the emotional labour, role and burden that were placed on the non-CF sibling, some of them recognised and voiced their need for help as opposed to complaining of physical/somatic symptoms themselves as discussed by Knecht (2015). In doing so they stated ways in which they were resourceful in gaining such help, which included turning to friends, talking to teachers in school, talking to the researcher and in previously talking to their mum, (but when talking to mum this was guarded so as to maintain peacekeeping and protection within the family). Others did not state that they spoke to anyone.

This study was not set up to be a short-term therapeutic intervention study like Murray (2001), Simms (2002), Essen and Enskar (2003), Bransetter (2008) and Gursky (2007). However an unexpected unique contribution was that this study did provide a therapeutic intervention by its very nature of the study design in terms of having four visits with each family and using multiple creative research methods, as well as shifting the family dynamic. It was in their 'after word' that siblings and their families stated that being involved in this study had helped them because in talking to the researcher they had been given a centre stage

opportunity to open up and talk about their worries, concerns and experiences. It had enabled them to express feelings and emotions in their back stage stance that, they had previously not demonstrated, had concealed or had internalised. In being a participant in the study and having the time during the visit and between visits to perform and be creative, it also opened up a window of opportunity for family communication as a whole with the non-CF sibling, so parents became more aware of sibling concerns. The protagonists added to the discussion stating that they enjoyed being part of the study and they enjoyed having the one to one attention and making their pictures. This highlights the need for further research in this area to assess the long term benefits of having a creative study as a therapeutic intervention to enable siblings with CF to express/explore their feelings, emotions and enhance family communication.

9.8 IMPLICATIONS FOR PRACTICE AND POLICY

It is essential that practitioners and policy makers have greater awareness and insight into the daily impact on siblings when living with a brother and or sister with the chronic disease of CF. There is also a need for greater emphasis to be placed on addressing these sibling's needs as a consequence of the opposing forces of the condition. Enhanced family centred care practices where healthcare professionals are more inclusive of the non-CF sibling within the hospital or home environment is advocated as a consequence of this study.

It is important that practitioners and policy makers understand that siblings present themselves in a multitude of ways and whilst they may appear to be okay and present being good, they do endure an emotional labour in the parallel journey with their brother and or sister along the CF trajectory. This is particularly noticeable when there is a new diagnosis, a complication, a major change in a treatment, or when there is a need for a child to move to transitional care. Siblings do take on additional roles and responsibilities on a daily basis that can be burdensome and they do

exhibit worries or concerns that can often be internalised. They may choose not speak about them because they want to be loyal in protecting their family members from further burdens, as they do not want to upset the equilibrium of family life or cause detriment to oneself. Siblings also have moments of limited (or no attention at all) when the focus is on their CF-sibling's treatment in the home. They also encounter moments of separation when their brother and or sister is in hospital and they express distress, upset and sadness in relation to missing their mothers in particular during these times. This can lead to moments of isolation and loneliness as well as impact on their positional/spatial status in the family because they do not have a centre stage position. Therefore there is a need for greater insight into the importance of the spatial/positional spaces of these children within the home.

It is important also for healthcare practitioners and policy providers to be aware of the emotional endurance of siblings living with brothers and or sisters with the disease. There should not be a taken for granted assumption or statement that refers to non-CF siblings as being well or healthy in the absence of them not having a physical disease, or because they may say that they are "fine" when they are not, because having a sibling with CF does have an impact on their wellbeing. Therefore these children should be encouraged to express how they feel and be provided with opportunities of support because in this study some of them recognised their own need for help and some of them did not despite exhibiting emotional performances. Therefore such support can be given in terms of one to one attention as siblings in this study stated that helped and it allowed non-CF siblings moments of centrality within their family when CF treatments were not being given. Healthcare professionals can be facilitators in opening and supporting family communication processes.

Siblings' value having one to one attention as it provides them with the opportunity to talk about their worries, concerns and experiences when living in the context of CF. It can also provide a positive distraction away

from being witness to daily CF treatments. Having one to one attention as well as having an opportunity to be placed in a more centrally placed position in their family by a healthcare professional, can also enable them to ask questions. This allows them to be provided with greater support in relation to their CF-siblings disease, particularly when they want to know more about it. Providing one to one attention or a platform for the centrality of the non-CF sibling within their family can also help with the facilitation of wider family communication as a whole. This can be in relation to discussing and exploring the key moments that are encountered within the CF trajectory. This would be useful because some children are reluctant to raise their concerns when they know that the CF child's needs are a priority.

It is important to provide a platform for the sibling to give their voice in relation to their experiences. In considering listening to and hearing the sibling voice, policy writers and practitioners must be aware that for siblings in middle childhood, their voice may not be in the spoken word as it can be in their overall interactive co-constructed performance within their familial cultural milieu. It is important to be aware that sometimes these children are not able to voice their concerns verbally and they may want another family member to advocate for them if they are unable to articulate the words themselves.

They may also choose to give their voice through a creative expression such as a picture, a song, a poem or a re-enactment. For siblings there are multiple ways to give voice and it is important to look beyond their front stage 'façade' to have greater understanding of their needs. It is important to observe, listen and interact with them in their performances to enable the build up a trust and rapport, which will allow these children to express what they really want to say in ways that they want to say it. Using creativity, sensory media as well as giving sibling's time to articulate their experiences can be helpful to them.

The suggestions above are transferrable to the care of siblings living with brothers or sisters with other chronic illnesses. A publication and dissemination plan is presented in Appendix 2.

RESEARCHER POSITIONING WITHIN THE FAMILY

At the outset of this study I had not anticipated how my study design and focus would completely shift the family dynamic in terms of positioning within this study. As the researcher visiting participants in their family home and drawing a focus of attention to the non-CF sibling instead of the CF sibling did provide a situation where the familiar was made strange for the family. They were in familiar surroundings with their family, but through researcher presence the dynamics of the family (as a team) became changed because the roles of the family altered in terms of who was normally centre stage and who was not the main focus of attention i.e the CF sibling. This shifting dynamic meant I witnessed a family transition along with some acting up behaviours from the CF child as they demonstrated a protest at not being centre stage and having a shift in their positional movement where they became witnesses of their non-CF sibling having the focus of attention. This was removed from the norm of family life. Despite this shift I did notice a change of acceptance and understanding of the CF sibling and other family members in relation to these temporal moments of unfamiliarity. An example is provided here that demonstrated this acceptance with one family that I was observed as the researcher where in one family the CF sibling who had been acting up on my first couple of visits, became welcoming by the fourth visit and actually set up a stage set in the family study where myself and her brother Raff could sit and look at family photos. This shifting dynamic was significant and very powerful to experience. It highlights the importance, particularly for childhood studies for the researcher to consider the changes to family dynamics when conducting a study and how a study design that enables the researcher to visit a child and family on several occasions may be beneficial for the family members as a team. It is also beneficial in gaining research findings that are not merely front stage. Had

I only visited each family on one occasion I would not have recognised the shift in roles in making the familiar seem strange. I recognise that having four visits with each family not only extends the value and contribution of this study, but most importantly it highlights the privilege that I was given by the families in being allowed to spend quality moments of time with them. Without their welcoming and acceptance of me in their home, this study would not have been possible. Shifting of the family dynamic whilst risky was also beneficial, because this longitudinal study opened up subtle channels of communication and interactions of family life. As a consequence this added to the therapeutic value of the work.

LEAVING THE FIELD

In terms of my researcher positioning I also had to plan an exit strategy for the end of my study and this presented an emotional challenge for myself and for some of the children. Over the four visits siblings and their families had invited me into their home, their lives, also into their back stage worlds. Within this experience the family built up a trust with me and some powerful performance narratives were shared by the siblings and family members and included presentations of emotional selves. Whilst I remained professional whilst I was with the family, I could not help but take away with me the emotional burden of their stories, which presented an emotional burden for me as the researcher, as well as my recognition of the containment of the emotional reactions of the siblings and family members. This made exiting difficult because I did recognise that some of the siblings and families would have preferred me to continue with more visits.

I would argue that there does need to be a consideration when planning such studies. This is especially so in terms of the impact the researcher has on being with the family when they are conducting a longitudinal study - particularly when children and families have seen some therapeutic value. Whilst systems were in place in this study if children needed referral to their GP or a psychologist none of these referrals were

necessary. However, this study now leads me to question the exit strategy of the researcher and highlights the need for greater flexibility in exiting the field and for a flexible approach based on individual need, particularly if a family would benefit from a weaning off of visits, or gradually shorter visits. All of the families were provided with my contact details and were aware they could contact me in relation to any aspect of the study.

RESEARCHER POSITIONING WITHIN THE STUDY

It needs to be restated within this work that I have conducted this study with the subject position of being a qualified children's nurse with over 25 years of children's nursing experience. Having prior experience and knowledge expertise in working with children and families proved beneficial because I was readily able to engage and adapt to situations that I faced within when spending time with these families. It is also noted that I set up and led a children's respiratory service and worked as a clinical nurse specialist in primary and secondary care settings for eight years prior to moving into education in children and young people's nursing. Whilst I presented myself as a researcher, families became aware of my background and this added to their acceptance of me into their worlds. They could see that I was genuine, relevant and authentic with my interest as I was able to understand their CF child's condition and the need for their treatments and they became aware that I had visited children with CF and families in their homes as a nurse. However, what my nursing experience could not prepare me for was how different I saw the family world in visiting them as a researcher. This difference was influenced by not only the change in the dynamic of my role but also because children were the key participants of this study and it was they who guided the work.

9.9 LIMITATIONS AND FURTHER RESEARCH

It needs to be acknowledged that whilst this study has presented insight into the sibling worlds in terms of their experience of living in the context of CF, it only represents one small cohort of individuals within a given time frame so its temporality only provides a snapshot of their world. Further research is recommended in exploring the experiences of a larger cohort of non-CF sibling participants to include those from differing age groups as this study only represents those in middle childhood.

Whilst children were the key participants of this work, two participants did not complete all of the four participatory time schedules/activities. One child completed three out of the four visits and one child completed two of the four visits. Therefore for these two children, the full complement of participation was not achieved and this will have impacted on the data collected. However, due to the flexible nature of the project, for one of the children the research questions were all answered within the three scheduled participatory appointments that were engaged in. What I was unable to conclude was why the children ceased to be participants and if the decision to not continue was the child's or that of their parent? Despite the non-completion of these two participants there was enough data generated to be able to meet the outcomes of this study in addressing the research questions.

Exploring the experiences of siblings with their family within their home /cultural milieu generated some new insights into their use of space, positioning, social interaction and self-presentation. However wider insights could be gained from studying how the non-CF siblings present themselves in other cultural groups/environments, such as in school or a place external to the home. It would also be useful to see how the non-CF siblings interact and present themselves within their friendship groups/their peers and teachers.

Whilst non-CF siblings provided their voiced performance in relation to their experience of when their brother and or sister was admitted to hospital, the study did not capture an observation of the immediate lived performance/interaction of this time or their experience during a CF sibling hospital admission or a CF nurse visit. Observation/narrative inquiry at such moments of separation/intervention would add to the insight of the sibling experience.

In terms of ethnicity the study can be criticised for its lack of diversity in only focusing on siblings of white Caucasian ethnic origin. However, this is the predominant population/ethnicity for this disease. There can be prevalence in other ethnicities but it is rare, as was identified in the literature review and so there were no available participants of other ethnicities with the disease to invite into the study.

Using a dramaturgical framework as the lens in which to view the sibling experiences in the context of their family can be criticised because Goffman's (1959) framework is not without its limitations. Buss and Briggs (1984) suggests the model can be criticised because it does assume that everyone is in role at all times moving between front stage and backstage positions and they suggest it does not account for what happens off stage when a person is alone or with a real or imagined audience. This limitation is counteracted in this study because 'off stage place' is identified and discussed in order to extend the work of Goffman (1959). Also asking children to prepare visual and creative activities when the researcher was not present has allowed some 'on your own' moments to be captured within the narrative inquiry. Buss and Briggs (1984) highlight another limitation of Goffman (1959) suggesting that a participant may feel under scrutiny when on stage and as a consequence they may alter their behaviour so it is suitable to the context of the situation. Having four visits with each sibling and their family was helpful in overcoming this weakness because it enabled the researcher to move beyond front stage

presentations. Also using several research methods was useful in capturing contradictions within the social interaction situations.

Providing an adult interpretation of the data generated could be criticised in terms of highlighting and maintaining the sibling voice (Leitch 2008, Manning 2015). Through the use of creativity in presenting a 'Three Act Play' to bring this work alive, I have made the strongest attempts possible to maintain the sibling performance vocalisations to preserve their authenticity because they were the key participants and narrators of the work. This is demonstrated with the presentation of their narratives, songs, poems, pictures and discussion of any presented artefacts. Presenting an array of visual and creative media along with my own transparency of researcher reflexivity has aimed to ensure the quality and credibility of this research. The importance of maintaining such researcher credibility is acknowledged in the work of Manning (2015) who also used an array of creative research methods and Richardson (2015).

If I were to conduct this study again I would choose to conduct a longitudinal study over a period of one year whereby I could spend longer periods of time with the children within the context of their family to gain further insight into non-CF sibling lives to include significant events and times of parent/sibling separation if a CF child is admitted to hospital. It would be useful to extend the context of the study to explore different sibling environments such as when they are in school or with a social group or when they are with their friends, as this would add to the understanding of their self-presentations when they are away from their family members and environment. It would also be useful to do a future follow up study to see how these early experiences in middle childhood have influenced their future self.

9.10 CONCLUSION

This is the first study within the UK that has explored the experiences of siblings in the age range of middle childhood, when living with a brother

and/or sister with cystic fibrosis through the use of narrative inquiry, visual methods and creativity. Using a bricolage of creative participatory methods has enabled non-CF siblings to express their multiple voiced selves through constructed and co-constructed interactive performances within their family home environment. Using a dramaturgic lens through which to view the experiences and interpret the data collected has provided insight into temporal moments of their lives. These moments of performance and acts build up segments of a collective mosaic to formulate an overall sibling portrait that can add to knowledge within the literature and can influence developments in practice and policy, to enable a greater understanding of non-CF siblings and how they can be helped in their worlds. Further research is recommended particularly in relation to exploring sibling presentation of self in school and with friends or in other social activities external to the home when living with a brother and or sister with CF.

10. REFERENCE LIST

- Adams R (2012) *Working with children and families. Knowledge and contexts for practice*. London. Palgrave Macmillan
- Ahmann E (2006) Supporting father's involvement in children's health care. *Pediatric Nursing* **32**: 88-90
- Alderfer MA, Long KA, Lown EA, Marsland AL (2010) *Psychosocial adjustment of siblings of children with cancer: A systematic review*. *Psycho-oncology*. 19 (8) 789-805
- Alderson P (2000) *Young Children's Rights. Exploring beliefs, principles and practice*. London. Jessica Kingsley.
- All Wales Child Protection Procedures (2008), *Safeguarding Children: Working Together under the Children's Act 2004* (2007).
- American Academy of Pediatrics/ Institute for family-centered care (2003) Family Centred care and the Pediatricians Role. *Pediatrics* 112 (3) 691-696
- Anning A and Ring K (2004) *Making sense of children's drawings*. Berkshire. Open University Press McGraw-Hill education.
- Archard D (1993) *Children: Rights and Childhood*. London. Routledge.
- Archard D (2015) *Children: Rights and Childhood Third Edition*. Oxon. Routledge.
- Aries P (1962) *Centuries of childhood*. London. Jonathan Cape.
- Aries P (1973) *Centuries of childhood*. Harmondsworth. Penguin.
- Aries p (1960; 1986) *Centuries of childhood*. Harmondsworth. Penguin.
- Baillie J, Lankshear A, Featherstone K (2012) Perspectives on peritoneal dialysis at home: implications for the management of a chronic condition. A study protocol. *Journal of Advanced Nursing*. 68, 1847 – 1857. Blackwell Publishing Ltd.
- Bagnoli A (2004) Researching identities with multiple-method autobiographies. *Sociological Research Online* [online] 9. <http://www.socresonline.org.uk/9/2.html> (accessed 08/08/2015)
- Bagnoli A (2009) Beyond the standard interview. The use of graphic elicitation and arts based methods. *Qualitative Research*. 9 (5) 547-570

Bak IM and Ross HS (1996) I'm telling! The content, context and consequences of children's tattling on their siblings. *Social Development*. 5 (3) 292-309

Bakhtin J J (1986) *Speech genres and other late essays*. Austin: University of Texas Press.

Bakhtin J J (1981) *The dialogic imagination*. Austin: University of Texas Press.

Balen R, Holroyd, Mountain G, Wood B (2000/2001) Giving children a voice: Methodological and practical implications of research involving children. *Paediatric Nursing* 12 (10) 24 – 29

Bales RF and Parsons T (2014) *Family: Socialization and the Interaction Process*. London. Routledge.

Balfour-Lynn LA, Elborn JS (2007) Respiratory Disease: Infection, (chapter 10) in Hodson, Bush and Geddes (2007) *Cystic Fibrosis* . Third Edition. London. Hodder Arnold.

Bamberg M (2004) Positioning with Davie Hogan. Stories, Tellings, and identities. 135-157 In Dauite C and Lightfoot C 2004 *Narrative Analysis. Studying the Developmental of Individuals in Society*. London. Sage.

Bamberg M and McCabe A (1998) "Editorial". *Narrative Inquiry* 8 (1) iii-v

Banks, M. (2001) *Visual Methods in Social Research*, London: Sage

Bank SP and Kahn MD (1982) *The Sibling Bond*. New York. Basic Books

Barker ET, Hartley SL, Seltzer MM (2011) Trajectories of Emotional Well-Being in Mothers of Adolescents and Adults with Autism. *Developmental psychology* 47 (2) 551-561

Beacham BL, Deatrick JA (2015) Children with chronic conditions: Perspectives on condition management. *Journal of pediatric nursing*. January-February 30 (1) 25- 35

Barrera M, Fleming CF, Khan FS (2004) The role of emotional social support in the psychological adjustment of siblings of children with cancer. *Child: care, health and development* 30 (2) 103-111

Beck C (2002/2003) "*The Enchanted Garden*": a challenging image in children's literature. Thesis. Submitted to the University of Nottingham.

Bedford VH, Volling BL, Avioli PS (2000) Positive consequences of sibling conflict in childhood and adulthood. *The international journal of aging and human development* 51 (1) 53-69.

Bell N.W and Vogel EF (1960) Ed. *A Modern Introduction to the Family*. London. Routledge and Kegan Paul.

Bell, S.E. (1999) "Narratives and lives: Women's health politics and the diagnosis of cancer for DES daughters". *Narrative Inquiry* 9(2):1-43.

Bellin MH and Kovaks PJ (2006) Fostering resilience in siblings of youths with a chronic health condition: A review of the literature. *Health and Social Work*. 31 (3) 209-216.

Berge J M, Patterson JM , Ruieter M (2006) Marital satisfaction and mental health of couples with children with chronic illness. *Families, systems and Health*. 24 (3) 267-285

Bergemen CS and Wallace KA (1999) Resiliency in later life, ch 11 207 – 226 in Whitman TL, Merluzzie T V, White RD (1999) *Life Span perspectives on health and illness*. New Jersey. Taylor Francis.

Berger, P. and Luckman, T. (1966) *The Social Construction of Reality*. New York: Doubleday and Co.

Berkvam DD (1983) Nature and Nurture: A notion of Medieval Childhood and Education. *Mediavallia*. In Heywood (2001) *A History of Childhood: Children and Childhood in the West from Medieval to Modern Times*. Oxford. Blackwell.

Berns U (2013) *Performativity in Huhn P, Schmid W Schonert J (2013) The living handbook of narratology*. Hamburg. Hamburg University Press

Bertrand, I. and Hughes, P. (2005) *Media Research Methods: Audiences, Institutions and Texts*, Basingstoke: Palgrave Macmillan

Bill S and Hodges B (2007) Transitional Care (Chapter 10) in Valentine F and Lowes L (2007) *Nursing Care of Children and Young People with Chronic Illness*. London. Wiley-Blackwell.

Bluebond-Langner, M. (1996/ 2000). *In the shadow of illness*. Princeton, NJ:Princeton University Press.

Bluebond-Langner M (1991) Living with Cystic Fibrosis The Well Siblings Perspective. *Medical Anthropology Quarterly. International Journal for the Analysis of Health*. 5 2 133-152

Bradley B S (1989) *Visions of Infancy: A critical introduction to child psychology*. Oxford. Polity.

Bransetter JE, Williams Domian E, Dauz Williams P, Graff JC, Piamjariyakul U (2008) Communication themes in families of children with

chronic conditions. *Issues in Comprehensive Pediatric Nursing*, 31, 4 171-184

Borland M (1998) *Middle Childhood: The Perspectives of Children and Parents*. London: Jessica Kingsley.

Borreca A (1993) Political Dramaturgy. A Dramaturg's (Re) View. *The Drama Review*, 37 (2) T138 56-77

Broderick PC and Blewitt P (2006) The emerging self and socialisation in the early years. *The lifespan: Human development for helping professionals* 2nd edition. New Jersey, Pearson Education.

Brody G H (1996) *Sibling Relationships: Their Causes and Consequences. Advances in applied developmental psychology*. New Jersey. Ablex publishing corporation.

Brody GH (1998) Sibling Relationships Quality: Its Causes and Consequences. *Annual Review of Psychology* 49 (1), 1-24

Brody G H (2004) Siblings' direct and indirect contributions to child development. *Current Directions in Psychological Science* 13 (3) 124-126

Brown R, Barber P, Martina D (2009) *Mental Capacity Act 2005: A guide for practice*. Padstow. Learning Matters LTD.

Brucefors AB, Hochwalder J, Sjoval J, Hjelte (2015) Depression and Anxiety among Parents of Children with Cystic Fibrosis Related to Children's Health Related Quality of Life. *Open Journal of Nursing*, 5, 482-489

Bruner J. (1986) *Actual Minds, Possible Worlds*. Harvard. Harvard University Press.

Bruner J. (1990) *Acts of Meaning*. Harvard. Harvard University Press.

Bruner J. (1991) The Narrative Construction of Reality. *Critical Inquiry* 18 (1): 1-21.

Bruner J., Feldman C (1993). Theories of Mind and the Problem of Autism, in *Understanding Other Minds: Perspectives from Autism*, edited by S. Baron-

Bruner, J. (2002) *Making stories: Law, literature, life*. New York: Farrar, Strauss and Giroux.

Buckingham D (2000) *After the Death of Childhood: Growing up in the Age of Electronic Media*. Cambridge. Polity.

Burke K (1972) *Dramatism and Development*. Barre MA. Clark University Press with Barre Publishers.

Burnard P, Morrison P and Heather Gluyas (2011) *Nursing Research in Action. Exploring, understanding and developing skills*. Third Edition. London. Palgrave Mcmillan

Burr V (2015) *Social constructionism*. Third edition. Oxford. Routledge

Buss A. H, Briggs S.R, (1984) Drama and the Self in Social Interaction. *Journal of Personality and Social Psychology*. 47 (6) 1310-1324

Butler J (1997) *Excitable Speech: A politics of the performative*. London. Routledge.

Butler – Kisber L (2010) *Qualitative Inquiry: Thematic, Narrative and Arts-Informed Perspectives*. London. Sage.

Cardiff University (2009a) Health and Safety in Fieldwork/Fieldwork Policy <http://www.cardiff.ac.uk/osheu/resources/Health%20and%20Safety%20in%20Fieldwork%20Policy%20and%20Guidance.doc> (Accessed 1/10/2011)

Cardiff University (2009b) *Research Governance Framework Document*. Cardiff. Cardiff University.

Cardullo B (2014) *What is dramaturgy?* Switzerland. Peter Lang AG

Casey A. (1988) A partnership with child and family. *Senior Nurse* 8 (4) 8-9

Cashin G, Small S, Solberg S (2008) The lived experience of fathers who have children with asthma: A phenomenological study. *Journal of Pediatric Nursing* 23 (5) 372 -84

Charlesworth, Wood and Viggiani (2011) Middle Childhood In Hutchinson ED (2011) *Dimensions of Human Behaviour. Changing the life course. Fourth Edition*. Chapter 5. Thousand Oaks CA. Sage

Charmaz K (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health and illness*, 5 (2) 168-195

Chase, S.E. (2005) 'Narrative inquiry: Multiple lenses, approaches, voices'. In N.K. Denzin and Y.S. Lincoln (eds.), *The Sage Handbook of Qualitative Research*, 3rd ed. Thousand Oaks CA: Sage, pp. 651-679.

Cheal D (2002) *Sociology of family life*. Basingstoke. Palgrave

- Chuckry A (1990) The philosophical trinity. In School of Healthcare Science. *Exploring epistemologies of practice. Module Guide* (2014) unpublished. Cardiff. Cardiff University.
- Cicirelli V G (1995) *Sibling Relationships Across the Lifespan*. New York. Plenum Press.
- Clarke D (2014) *The Experience of Gay Male Undergraduate Nursing Students: A qualitative exploration of professional lives*. PhD Thesis. Cardiff University.
- Clarke S and Hoggett P (2009) *Researching beneath the surface: Psychosocial research methods in practice*. Great Britain. Karnac.
- Clarke L and Ungerer JA (2007) Children's drawings provide a new perspective on teacher-child relationship quality and school adjustment. *Early childhood research quarterly* (22) pp55
- Coad J, Gibson F, Horstman M, Milnes L, Randall D, Carter B (2015) Be my guest! Challenges and practical solutions of undertaking interviews with children in the home setting. *Journal of Child Health Care*, 19 (4) 432-43
- Coad J (2012) Involving young people as co-researchers in a photography project. *Nurse Researcher* 19 (2) 11-16
- Coad J, Plumridge G, Metcalfe A (2009) Involving children and young people in the development of art-based research tools. *Nurse Researcher* 16 (4) 56-64
- Cocks A and Adams R (2012) Working ethically with children. Chapter 16 in Adams R (2012) *Working with children and families. Knowledge and contexts for practice*. Hampshire. Palgrave.
- Coffey J S (2006) Parenting a child with chronic illness: A metasynthesis, *Pediatric Nursing* 32 (1) 51 – 58
- Coles P (2003) *The importance of Sibling Relationships in Psychoanalysis*. London. Karnac Books.
- Coleman V (2010) 'The evolving concept of child and family centred care' in Smith S and Coleman V (2nd ED) *Child and family-centred healthcare. Concept, theory and practice*. Basingstoke. Palgrave. Chapter one. PP 1 - 21

- Coleman V, Smith L and Bradshaw M (2003) Enhancing consumer participation using the Practice Continuum Tool for family-centred care. *Paediatric Nursing*. 15 (9)
- Collier, M. (2001) 'Approaches to Analysis in Visual Anthropology', in T. van Leeuwen and C. Jewitt (eds.) *Handbook of Visual Analysis*, London: Sage, pp. 35-60
- Cooley C H (1964) *Human Nature and the Social Order*. New York. Transaction Books.
- Corlett J and Twycross A (2006) Negotiation of parental roles within family centred care: review of research. *Journal of Clinical Nursing*. 15 (10) 1308-16
- Court Report (1976) *Fit for the Future: The Report of the Committee on Child Health Services*. Volume One. London: HMSO.
- Cowen L, Mok J, Corey M, McMillan H, Simmons R, Levinson H (1986) Psychological adjustment of the family with a member who has cf. *Pediatrics*, Volume 77,743-753
- Coyne I & Crowley S (2007) Challenging the philosophy of partnership with parents: a grounded theory study. *International Journal of Nursing Studies* 44, 893–904.
- Coyne I & Gallagher P (2011) Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of clinical nursing*. 20, 2234-2343.
- Cresswell J (2014) *Research Design. Qualitative, Quantitative and Mixed Method approaches. Fourth edition*. London. Sage.
- Cronin de Chavez, A., Backett-Milburn, K., Parry, O. and Platt, S. (2005) Understanding and Researching Wellbeing: Its usage in different disciplines and potential for health research and health promotion. *Health Education Journal*, 64(1), 70-87
- Children's Act (2004) Explanatory Notes Chapter 31. London. HM Government. Stationary Office.
- Csikszentmihalyi M. (2000). *Beyond Boredom and Anxiety: Experiencing Flow in Work and Play*. San Fransisco, Jossey-Bass.
- Culling JA (1988) The psychological problems of families of children. In Oakhill A (ed) *The supportive care of the child with cancer*. Bristol. John Wright.

Cunningham H (1991) *The Children of the Poor. Representations of Childhood since the Seventeenth Century*, Oxford. Basil Blackwell.

Cystic Fibrosis Trust (2012) www.cftrust.org.uk/accessed1/08/2012

Cystic Fibrosis Trust (2015) *Cystic Fibrosis strength in numbers. UK CF Registry Survey Report . February / March 1-17*. London. Cystic Fibrosis Trust.

Daiute C and Lightfoot C (2004) *Narrative Analysis. Studying the development of individuals in society*. London. Sage.

Dale N (1996) *Working with families of children with special needs. Partnership and practice*. London. Routledge.

Data Protection Act (1998)

http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_1. (Accessed 20/10/2011)

David M and Sutton C (2011) *Social Research an introduction*. Second edition. London. Sage

Davies P R (2013) *Rethinking Biblical Scholarship: Changing Perspectives*. London. Routledge.

Davis M., K. Dautenhahn, C.L. Nehaniv, S.D. Powell (2003). Coherent Worlds - The Role of Narrative in the Creation of Meaning. *Proceedings of the 7th International Autism-Europe Congress*, Lisbon: pp 399-400

Denzin N.K and Lincoln Y.S. (eds) (1998) *Strategies of Qualitative Inquiry*. London. Sage

Denzin N.K and Lincoln Y.S (eds) (2000) *Handbook of Qualitative Research*. Second Edition. London.Sage.

Department for education and skills (2003) *Every Child Matters*. London. DFES.

Department of education and skills (2005) *Departmental Report*. London. HMSO.

Department of Health (2011) *Children and young people's emotional wellbeing and mental health national support team. The learning: what good looks like*. London.

Department of health (2010) *Achieving equity and excellence for children. How liberating the NHS will help us meet the needs of children and young people*. London. DOH.

- Department of Health (2011) *Better care: better lives*. NHS East of England. DOH.
- Department of Health (2012) *Liberating the NHS: No decision about me, without me. Further consultation on proposals to secure shared decision-making*. London. DOH.
- Department of Health (2009) *Healthy lives, brighter futures – The strategy for children and young people’s health*. London. DOH.
- Department of Health (2008) *High Quality Care for All*. London. DOH.
- Department of Health (2005) *Research Governance for Health and Social Care*. London. DOH.
- Department of Health (2003) *Listening, hearing and responding. Department of health involving children and young people*. London. DOH.
- Department of Health and Social Security (1976) *Fit for the future: The Court Report*. London. HMSO.
- Dockett S and Perry B (2011) Researching with children: Seeking Assent. *Child Indicators Research*, 4 (2) 231 – 247
- Doherty K and Coleridge G (2010) *Sibling Rivalry: Seven Simple Solutions*. Ealing. Bantam Press.
- Donaldson M (1978) *Childrens Minds*. Glasgow. Fontana/Collins.
- Dreissnack M (2006) Draw-and-tell conversations with children about fear. *Qualitative Health Research*. 16 (10) 499-509
- Dunbar SB (1999) A child’s occupational performance: Considerations of sensory processing and family context. *American Journal of Occupational Therapy*. 53, 231-235.
- Dunn J and Kendrick C (1982) *Siblings, Love, Envy and Understanding*. London. Grant McIntyre.
- Dunn J (2008) Sibling Relationships across the Life-Span. In Klett-Davies M ed *Putting Sibling Relationships on the Map. A Multidisciplinary Perspective*. London. Family and Parenting Institute.
- Dunst CJ and Trivette CM (1996) Empowerment, effective help giving

practices and family-centered care. *Paediatric Nursing* 22 (4) 334 -7 343.

Durant-Law G (2005) Soft systems methodology and grounded theory combined: a knowledge management research approach. *Online journal of knowledge management*. 2 (1) 13-23

Edwards R, Hadfield H and Mauthner M L (2005) *Children's Understanding of their Sibling Relationships*. National Childrens Bureau for the Joseph Rowntree Foundation.

Edwards R, Hadfield L, Lucey H and Mauthner M (2006) *Sibling Identities and Relationships: Sisters* London: Routledge.

Elkind D (1981) *The Hurried Child: Growing up too fast too soon*. Reading, MA: Addison-Wesley

Ellis E E (1992) *The Old Testament in Early Christianity*. Ada, MI 49301. Baker.

Emmel N (2013) *Purposive work in a realist sampling strategy. Sampling and choosing cases in qualitative research. A realist approach*. London. Sage

Engel S (2005) Narrative analysis of children's experience (Chapter 11) in Greene S and Hogan D (2005) *Researching Children's experience: Approaches and Methods*. London. Sage.

Essen LV and Enskar K (2003) Important aspects of care and assistance for siblings of children treated for cancer. *Cancer nursing* 26 (3) 203 – 210

Fanos JH and Johnson JP (1995) Perception of Carrier Status by Cystic Fibrosis Siblings. *American Journal Human Genetics*. 57:431-438,

Fergus M, Almond, P, Baker C, Forbes D, Wilson L (2010) Promoting Family Health in Contemporary Healthcare. In: A Glasper, M Aylott, C Battrick (eds.) *Developing Practical Skills for Nursing Children and Young People*. London: Hodder Arnold

Fidika A, Herle M, Lehmann C, Weiss C, Knaevelsrud C and Goldbeck L (2015) A web-based psychological support program for caregivers of children with cystic fibrosis: A pilot study. *Health and Quality of Life Outcomes*. 13:11

Fineman S (1993) *Emotion in Organisations*. London Sage.

Fischer F (1998) Beyond Empiricism: Policy inquiry in postpositivist perspective. *Policy Studies Journal* 26 (1) 129-146

Fivush R and Nelson K 2004 culture and language in the emergence of autobiographical memory. *Psychological science*. 15 (9) 573 - 577

Fleet A and Britt C (2011) Seeing Spaces inhabiting places. Hearing school beginners. In Harcourt D Perry B and Waller T (2011) *Researching Young Children's Perspectives: Debating the Ethics and Dilemmas of educational research with children*. Oxon. Routledge

Flume PA, Liou TG, Borowitz DS, Li H, Yen K, Ordenez CL, Geller DE (2012) Ivacaftor in subjects with cystic fibrosis who are homozygous for the F508del-CFTR mutation. *Chest Journal*. 142 (3) 718-724.

Folkesson A, Jelsbak L, Yang L, Johansen HK, Ciofu O, Hoiby N, Molin S (2012) Adaptation of *Pseudomonas aeruginosa* to the cystic fibrosis airway: an evolutionary perspective. *National Review Microbiology*. 10 (12) 841-851

Foster C, Eiser C, Oades P, Sheldon C, Tripp J, Goldman P, Rice S and Trott J (2001) Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts. *Child: Care, Health and Development*. 27 (4) 349-364

Foster KA, Yazdanian M and Audus K.L (2001) Microparticulate uptake mechanisms of in-vitro cell culture models of the respiratory epithelium. *Journal of Pharmacy and Pharmacology*. (53) 57-66

Franck, LS and Callery, P (2004) Re-thinking family centered care across the continuum of children's healthcare. *Child: Care, Health and Development*. 30 (3) 265-277

Frankl V (1959) *Mans search for meaning; An introduction to logotherapy*. New York. Beacon Press.

Friedman S (1998) (Inter) disciplinary and the question of women's studies PhD *Feminist Studies* 24, 2

Freud S (1962) *Three Essays on the Theory of Sexuality*. 3 The definitive edition translated and revised by James Strachey. United States. Basic Books.

French JRP and Caplan RD (1973) *Organizational Stress and Individual Strain in A.J. Marrow Ed, The failure of success*. New York. AMACOM.

Frost, M, Green, A, Gance-Cleveland, B and Kersten, R (2010) Improving family centred care through research. *Journal of Pediatric Nursing*. 25, 144-147

- Fury G, Carlson EA, Sroufe LA (1997) Children's representations of attachment relationships in family drawings. *Child Development*. 68 (6) 1154-1164
- Gayton WF, Friedman SB, Tavormina JF, Tucker F (1977) Children with cystic fibrosis: I. Psychological test findings of patients, siblings and parents. *Pediatrics* 59 (6) 888-894
- Gergen, K.J. (1994) *Realities and Relationships: Soundings in Social Construction*. Cambridge, MA: Harvard University Press.
- Gergen, K.J. (1985) The social constructionist movement in modern psychology. *American Psychologist*, **40**, 266-275.
- Giddens A (1976) *New rules of sociological method: A positive critique of interpretative sociologies*. New York. Basic Books
- Gittins D (1998) *The child in question*. Hampshire. Macmillan Press LTD.
- Gursky B (2007) The effect of educational interventions with siblings of hospitalized children. *Journal of developmental and behavioural pediatrics* 28 (5) 392-398
- Goffman E (1959) *The presentation of self in everyday life*. Garden City, NY, Doubleday.
- Goffman E (1969) *Where the action is. Three essays*. London. Allen Lane Penguin press.
- Goffman E (1974) *Frame analysis*. New York. Harper and Row
- Goffman E (1990) *The presentation of self in everyday Life*. London. Penguin
- Goldenthal P (2000) *Beyond Sibling Rivalry: How to Help Your Child Become Cooperative, Caring and Compassionate*. New York: Henry Holt Company.
- Gubrium JF, Holstein JA (2002) *Handbook of interview research: Context and Method*. California. Sage.
- Hadfield L, Mauthner M, Edwards R (2005) *Children's Understanding of their Siblings Relationships*. London. Jessica Kingsley Publishers
- Hadfield L, Edwards R and Mauthner M (2006) Brothers and Sisters: a source of support for children in school? *Education* 3-31 34 (1) 65-72

- Harder L and Bowditch B (1982) Siblings of children with cystic fibrosis: Perceptions of the impact of the disease. *Children's Health Care*. 10 (4) 116-120
- Hastings RP (2003) Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of autism and developmental disorders*. 33 (2) 141-150
- Hamama L, Ronen T and Rahav G (2008) Self-control, self efficacy, role overload and stress responses among siblings of children with cancer. *Health and social work* 33 (2) 121 – 132
- Hammersley M and Atkinson P (1995) *Ethnography: Principles in practice, Second Edition*. London. Routledge.
- Harcourt D, Perry B, Waller T (2011) *Researching young children's perspectives. Debating the ethics and dilemmas of educational research with children*. London. Routledge.
- Hart R (1997) *Children's participation: The theory and practice of involving young citizens in community development and environmental care*. Florence, UNICEF Innocenti Research Centre.
- Havermans T, Wuytack L, Deboel J, Tijgat A, Malfroot A, De Boeck C, Proesmans M (2011) Siblings of children with cystic fibrosis: quality of life and the impact of illness. *Child: Care, Health and Development* 37 (2) 252-260
- Hay P (2014) *American Dramaturgy: A Critical Re-appraisal* in Cardullo B (2004) *What is Dramaturgy?* New York. Peter Lang.
- Hermans H J M (2001) The Dialogical Self: Toward a Theory of Personal and Cultural Positioning. *Culture Psychology* 7 (3) 243-281
- Heywood C (2004) *A History of Childhood: Children and Childhood in the West from Medieval to Modern Times* (Themes in History). Cambridge. Polity
- Higham S (2011) Family – centred care and the evolving role of fathers in Davies R and Davies A (EDS) (2010) *Children and young people's nursing, principles for practice*. 31 -51. London. Hodder Arnold
- Higonnet A (1998) *Pictures of Innocence: the History and Crisis of Ideal Childhood*. London. Thames and Hudson

- Hill M et al. (1996) Engaging with primary-aged children about their emotions and well-being: Methodological considerations. *Children and Society* 10 (2) 129-144
- Hodson M, Geddes D and Bush A (2007) *Cystic Fibrosis*. Third edition. London. Edward Arnold.
- Hogget (2009) *Researching beneath the surface. Psycho social research methods in practice*. Great Britain. Karnac Books.
- Holland P (1992) *What is a child? Popular images of childhood*. London. Virago.
- Holland K and Rees C (2010) *Nursing: Evidence based practice skills*. Oxford. Oxford University Press
- Holliday EL, Harrison LJ and Mcleod S (2009) Listening to children with communication impairment talking through their drawings. *Journal of Early Childhood Research*. 7 (3) 244-263
- Hollidge C (2001) *Psychological adjustment of siblings to a child with diabetes* Health and Social Work 26 (1): 15 -25
- Holloway I and Freshwater D (2007) *Narrative Research in Nursing*. Oxford: Blackwell
- Hollway W and Jefferson T (2000). *Doing qualitative research differently*. London. Sage.
- Houtzager BA (2004) *Siblings of Pediatric Cancer Patients: Coping, Risk Factors and Psychological Health*. Thesis Dissertation.
- Howe N, Aquan-Assee J, Bukowski WM, Lehoux PM and Rinaldi CM (2001) Siblings as Confidants: Emotional Understanding, Relationship Warmth and Sibling Self-Disclosure. *Social Development* 10 (4) 439-454.
- Hughes M (2007) Parents' and nurses' attitudes to family centred care: An Irish Perspective. *Journal of clinical nursing*. 2341 – 2348
- Hughes G and Ferguson R (2004) *Ordering Lives: family, work and welfare*. Second edition. Oxon. Routledge.
- Hutchfield (1999) Family-centred care: a concept analysis. *Journal of Advanced Nursing* 29: 1178–1187
- Hwang P C, Lamb ME and Sigel IE (1996) *Images of Childhood*. New Jersey. Lawrence Erlbaum Associates.
- Institute for Family Centered Care (2012) *Core concepts of patient and*

family centered care. www.ipfcc.org accessed 1/10/12

James W (1890) *The principles of psychology*, volume 1. New York. Holt

James A and Prout A (2015) *Constructing and Reconstructing Childhood. Contemporary issues in the Sociological Study of Childhood*. Second Edition. London. Routledge.

James A and Prout A (2015) *Contemporary issues in the sociological study of childhood*. London. Routledge.

James A, Jenks C and Prout A (2005/2007) *Theorizing Childhood*. Cambridge. Polity Press.

Jenks C (1996) *Childhood*. London. Routledge.

Jenks C (2005) *Childhood*. Second Edition. London. Routledge.

Jenkins R (1996/2003) *Social identity*. London. Routledge

Jupp V (2006) *Purposive Sampling*. *The sage dictionary of social research methods*. London. Sage.

Kaminsky L, Dewey D (2002) Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology* 43 2 225-232

Katz L (2014) The compleat dramaturg. In Cardullo B (2014) *What is dramaturgy*. New York. Peter Lang.

Katz LG and McClellan DE (1997) *Fostering Children's social competence. The teachers role*. Washington DC: National Association for the Education of Young Children. ED.413 073.

Kearney KS, Hyle AE, (2004) Drawing out emotions: The use of participant-produced drawings in qualitative inquiry. *Qualitative Research* 4 (3) 361-382

Kelly MT (2007) Achieving family-centred care: working on or working with stakeholders? *Neonatal, Paediatric and Child Health Nursing*. 10(3), 4-11

Kellner D (1995) *Cultural Studies, Identity, and Politics Between the Modern and the Postmodern*. London. Routledge.

Kerem B, Rommens JM, Buchanon JA, Markiewicz D, Cox TK, Chakravati A, Buchwald M, Tsui LC (1989) Identification of the cystic fibrosis gene: genetic analysis. *Science* 8 245 (4922): 1073-80

- Kennedy I (2010) *Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs.* A review by professor Kennedy. London.
- Keyes D, Lassiter A, and Roberts GH (2006) Cystic Fibrosis. *Journal of Continuing Education Topics and Issues* 8 (1) 10-15
- Kincheloe JL and Steinberg SR (1997) *Changing Multiculturalism: New Times, New Curriculum (Changing Education Series).* Buckingham. Open University Press.
- Kivisto P, Pittman D (2007) *Illuminating social life: Classical and contemporary theory revisited.* London. Sage
- Knafel KA, Deatrick JA, Knafel G, Gallo A, Grey M and Dixon J (2013) Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing*, 28 523-535
- Knecht C, Hellmars C, Metzger S (2015) The perspectives of siblings of children with chronic illness. A literature Review. *Journal of Pediatric Nursing*, 30, 102-116
- Klassen A, Dix D, Cano SJ, Papsdorf M, Sung L, Klaassen RJ. (2008) Evaluating Family-Centered Service in Pediatric Oncology with the Measure of Processes of Care (MPOC-20). *Child Care Health Development* 35:16-22.
- Klein M (1988a) *Love, Guilt and Other Works, 1921-1945.* London. Virago.
- Klein M (1988b) *Envy and Gratitude and Other Works, 1946-1963.* London. Virago.
- Klett-Davies M (2008) *Putting Sibling Relationships on the Map: A Multi-disciplinary Perspective.* London. Family and Parenting Institute.
- Kuk K and Taylor-Couser JL (2015) Lumacaftor and ivacaftor in the management of patients with cystic fibrosis: current evidence and future prospects. *Therapy Advances in Respiratory Disease* 9 (6) 313-26
- Kuo DZ, Houtrow A J, Arango P, Kuhlthau KA, Simmons J M, Neff JM (2012) Family-Centered Care: *Current Applications and Future Directions in Pediatric Health Care*
- Kuo DZ, Mac Bird T, Tilford JM (2011) Associations of family-centred care with health care outcomes for children with special health care needs. *Maternal and Child Health Journal* 15 (6) 794-805

- Kupfer H (2011) Children's voices in early childhood settings' everyday concerts in Harcourt D, Perry B, Waller T (2011) *Researching Young Children's Perspectives*. Oxon. Routledge.
- Labay LE and Walco GA (2004) Brief report. empathy and psychological adjustment in siblings of children with cancer. *Journal of Pediatric Psychology* 29 (4) 309-314
- Labov W and Waletzky J (1967) Narrative analysis: Oral versions of personal experience in J. Helm (ed) *essays on the verbal and visual arts* (pp 12 -44) Seattle, WA American Ethnological Society.
- Laming P (2003) *The Victoria Climbe Inquiry*. Norwich. HMSO
- Laming p (2009) *The Protection of Children in England: A progress Report*. The Lord Laming Review. London. The national children's bureau.NCB.
- Langellier KM (2001a) *Storytelling in Daily Life*. Philadelphia. Temple UP.
- Langellier KM (2002b) "You're Marked": Breast Cancer, Tattoo and the narrative performance of identity. *In Narrative and Identity: Studies in autobiography, Self and Culture*, edited by J.Brockmeier and D Carbaugh. Amsterdam and Philadelphia: John Benjamins.
- Langellier KM and Peterson EE (2003) *Performing Narrative. The communicative practice of storytelling*. Philadelphia. Temple UP.
- Law M, Hanna S, King J, Kertoy M and Rosenbaum P (2003) Factors affecting family-centred service delivery for children with disabilities, *Child. Care Health and Development*, 29 (5) 357-366
- Lawson M (2002) *Crow Lake*. Great Britain. Chatto and Windus.
- Lee H (2009) *Biography: A Very Short Introduction*. Oxford. Oxford University Press.
- Lee N (2001) *Childhood and Society. Growing up in an age of uncertainty*. Buckingham. Open University Press.
- Lee P (2007) What does partnership in care mean for children's nurses? *Journal of Clinical Nursing*. 16 (3) 518 – 526
- Lee P (2004) Family involvement: are we asking too much? *Paediatric Nursing* 16 (10) 37–41.
- Leitch R (2008) Creatively researching children's narratives through images and drawings in Thomson P (2008) *Doing visual research with children and young people*. Chapter 3 Oxon. Routledge.

- Leitch R and Mitchell S (2007) caged birds and cloning machines: How student imagery speaks to us about cultures of schooling and student participation. *Improving School*, 10 (1) 53-71
- Levi-Strauss C (1969) *Structural analysis in linguistics and anthropology*. London. Basic Books
- Levi-Strauss C (1966) *The Savage Mind*. Chicago. University of Chicago Press.
- Linde C. (1993). *Life Stories, the Creation of Coherence*, Oxford Press.
- Linde C. (2001). Narrative and Social Tacit Knowledge. *Journal of Knowledge Management, Special Issue on Tacit Knowledge and Active Learning* 5(2): pp 160-171.
- Lomax H (2012a) Shifting the focus: children's image making practices and their implications for analysis. *International of Research and Method in Education*. 35 (3) 227-234
- Lomax H (2012b) Contested voices? Methodological tensions in creative visual research with children. *International Journal of Social Research Methodology*, 15 (2) 105-117
- Lomax H (2015) Seen and Heard? Ethics and agency in participatory visual research with children, young people and families. *Families , Relationships and Societies*, 4 (3) 493-502
- Lorek-Jezinska E (2002) Audience activating techniques and their educational efficacy. *Applied Theatre Researcher*, 3, 6/3
- Lucey H (2010) Families, siblings and Identities In Wetherell M and Mohanty CT (2010) *The Sage Handbook of identities*. London.Sage.
- Luckin R., B. du Boulay (1999). Ecolab: The Development and Evaluation of a Vygotskian Design Framework. *International Journal of Artificial Intelligence in Education* 10: pp 198-220.
- Lupton R (2015) *The Quality of Silence*. London. Little Brown
- Macks RJ and Reeve RE (2007) The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders* 37 (6) 1060-1067
- Madison GB (1988) *The Hermeneutics of Postmodernity : Figures and Themes*. Bloomington. Indiana University Press.

Madison D.S. (1998) Performance, personal narratives, and the politics of possibility in S Dailey ed *The Future of Performance Studies: Visions and Revisions*. National Communication Association. Annandale pp 276-286. Margolis.

Malinowski B (1930) Kinship. *MAN*. 30. 19-29

Mandleco B, Webb AEM (2015) Sibling Perceptions of living with a young person with Down syndrome or autism spectrum disorder: An integrated review. *Journal for Specialists in Pediatric Nursing*. 20 (3) 138-156

Mannay D (2010) Making the familiar strange: Can visual research methods render the familiar setting more perceptible? *Qualitative Research*, 4 (3) 361-382

Mannay D (2011) Taking Refuge in the Branches of a Guava Tree. The Difficulty of Retaining Consenting and Non-consenting Participants'. Confidentiality as an Indigenous Researcher. *Qualitative Inquiry* 17 (10) 962-964

Mannay D (2013) 'Who put that there... why why why?' Power games and participatory techniques of visual data production. *Visual studies* 28 (2) 136-146

Mannay D (2015) *Visual, Narrative and Creative Research Methods: Application, reflection and ethics*. London. Routledge.

Manning J.C. (2015) *Stories of Survival. Exploring long-term psychosocial well-being in childhood survivors of acute life threatening critical illness: A multiple-case study*. Unpublished PhD Thesis. University of Nottingham.

Markus H and Nurius P (1986) Possible Selves. *American Psychologist*. 41 (9) 954-969

Martindale A (1994) The child in the picture. A medieval perspective. In Diana Wood ed. *The church and childhood*, vol 31 of studies in church history. Oxford. Blackwell.

Martinez YJ and Ercikan K (2009) Chronic illnesses in Canadian children: what is the effect of illness on academic achievement, and and anxiety and emotional disorders. *Child: care, health and development*. 35 (3) 391-401

Mason J (2002) *qualitative researching*. 2nd Edition. London. Sage.

Matthews, J. (1999) *The Art of Childhood and Adolescence: The Construction of Meaning*, London: Falmer press

- Matutina R (2009) Ethical issues in research with children and young people. *Paediatric Nursing* 21 (8) 38 – 44
- Mauthner ML (2002) *sistering: Power and change in female relationships*. Eastborne. Anthony Rowe limited.
- McCarthy M (1997) Pluralism, invariance, and conflict. *The review of Metaphysics* 51, 1
- McColley SA, Ren LC, Schechter MS, Regelman WE, Pasta DJ, Konstan MW (2012) Risk factors for the onset of persistent respiratory symptoms in children with cystic fibrosis. *Pediatric Pulmonology*. 47: 966-972
- McCullough C and Price J (2011) Caring for a child with cystic fibrosis: The Children's Nurses Role. *British Journal of Nursing*, 20 (3)164 – 167
- McDonald L M (2009) *Forgotten Scriptures: The Selection and Rejection of Early Religious Writings*. Louisville, KY.
- McGuire S, Manke B, Eftekhari A, Dunn J (2000) Children's Perceptions of Sibling Conflict During Middle Childhood: Issues and Sibling (Dis) similarity. *Social Development*, 9, 2.
- McLaughlin H (2015) *Involving children and young people in policy, practice and research*. National Children's Bureau. London. NCB
- McMenamy J.M and Perrin EC (2008) the impact of experience on children's understanding of ADHD. *Journal of developmental and behavioural pediatrics*, 29 483-492
- McHale SM, Crouter AC, McGuire (1995) Congruence between mothers' and fathers' differential treatment of siblings: links with family relations and children's well-being. *Child Development*. 66116-128.
- McLeod J (2000) Qualitative Research as Bricolage. Paper presented at the Society for Psychotherapy Research Annual Conference, Chicago in Kincheloe (2001) Describing the Bricolage. *Qualitative inquiry*. 7 (6) 679-692
- Mead G R S (1934) *Mind, Self and Society. From the standpoint of social behaviour*. Edited and with introduction by Charles W Morris. Chicago. University of Chicago Press.
- Med.stanford.edu (2015) accessed 10/12/15
- Mehto K, Kantola V, Tiitta S, Kankainen T (2006) Interacting with user data- Theory and examples of drama and dramaturgy as methods of

- exploration and evaluation in user-centered design. *Interacting with computers* 18 977-995
- Melnyk BM, Feinstein NF, Moldenhauer Z and Small L (2001) Coping in parents of children who are chronically ill; Strategies for assessment and intervention. *Pediatric Nursing*. 27 6 548-558
- Metzger B (1957) *An introduction to Apocrypha*. New York. Oxford Publishing. P88
- Meyerhoff B (1978) *Number Our Days*. New York. Simon and Schuster.
- Mikkelsen and Frederickson (2011) Family centred care – a concept analysis. *Journal of Advanced Nursing*. 67 (5) 1152- 1162
- Miller T.G. (1984) "Goffman, Social Acting and Moral Behaviour". *Journal for the Theory of Social Behaviour*. 14 (2) 141-163
- Ministry of Health, Central Health Services Council (1959) *The welfare of children in hospital', Platt Report*. London: HMSO,
- Mishler E G. (1986) *Research Interviewing: Context and Narrative*. Cambridge Mass: Harvard University Press.
- Mitchell J (2003) *Siblings*. Cambridge. Polity.
- Mitchell P and Zeigler F (2013) *The Fundamentals of Developmental Psychology*. Second Edition. East Sussex. Psychology press.
- Monaghan CM, Hilliard ME, Cogen FR, Streisand R (2009) Night time Care giving Behaviours Among Parents of Young Children With Type 1 Diabetes. Associations with Illness Characteristics and Parent Functioning. *Families Systems and Health* 27 (1) 28 – 38
- Morgan M (2015) *Emotions, Feelings and Findings*. FIG Event. Cardiff University.
- Moule P and Hek G (2011) *making sense of research: an introduction for health and social care practitioners*. London. Sage.
- Morawski J (1997) The science behind feminist research methods. *Journal of Social Issues*. 53 (4) 667-681
- Moretz J (2010) Strengthening patient and family centred learning through webinars. *Paediatric Nursing*. 36 (3) 168
- Morse J.M (2000) Determining sample size. *Qualitative Health Research* 10 3-5

- Mulhall A (2003) In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*. 41 (3) 306-313
- Munn P and Dunn J (1989) Temperament and the developing relationship between siblings. *International Journal of Behavioural Development*. 12 443-451.
- Murdock G.P. (1960) The Universality of the Nuclear Family. In Bell and Vogel eds. *A modern introduction to the family*. London. Routledge and Keagan Paul.
- Murray JS (1999) Siblings of children with cancer: A literature review. *Journal of Pediatric Oncology Nursing* 16 (1) 25-34
- Murray JS (2000a) Attachment theory and adjustment difficulties in siblings of children with cancer. *Issues in Mental Health Nursing*. 21 (2) 149-169
- Murray JS (2000b) Understanding sibling adaptation to childhood cancer. *Issues in comprehensive pediatric nursing* 24 85-94
- Murray JS (2000c) A concept analysis of social support as experienced by siblings of children with cancer. *Journal of Pediatric Nursing* 15 (5) 313-322
- Murray J.S. (2001) Self concept of siblings of children with cancer– *Issues in comprehensive pediatric nursing* 24 85-94
- National Association for the Welfare of Children in Hospital (1984) *NAWCH Charter for children in hospital*. London. NAWCH.
- Nelson JL (1994) Parents, Children, and the Church in the Earlier Middle Ages. In Diana Wood Ed (1994) *The Church and Childhood*. Vol 31 of studies in Church History. Oxford. Blackwell.
- Nethercott S (1993) 'Family centred care: a concept analysis' *Professional Nurse*, 8 (12) 794 -797
- Newell R and Burnard P (2011) *Research for Evidence-Based Practice in Healthcare 2nd edition*. Oxford. Wiley Blackwell
- NHS Choices 2015 Cystic fibrosis-Treatment. www.nhs.uk/cysticfibrosis accessed 20/10/15
- National Institute for health and care excellence (2015) Guideline scope (final). Cystic fibrosis: diagnosis and management of cystic fibrosis. 1-10 www.nice.org.uk/guidance/GID-CGWAVE0736/documents/final-scope accessed 18/10/15

Nursing and Midwifery Council (2008) *The Code: Standards of conduct, performance and ethics for nurses and midwives*.

<http://www.nmc.uk.org/aFrameDisplay.aspx?DocumentID=3954>.

Accessed 21/10/ 2012

Nursing and Midwifery Council (2015) *The Code: Professional Standards of practice and behaviour for nurses and midwives*. London. NMC

Nomura K, Obato K, Keira T, Miyata Ryo, Hirakawa S, Takano K. Kohno T, Sawada N, Himi T and Takashi Kojima (2014) Pseudomas aeruginosa elastase causes transient disruption of tight junctions and downregulation of PAR-2 in human nasal epithelial cells. *Respiratory Research* 15 (21) 1-13

Novac M and Guest C (1989) Application of a Multidimensional Caregiver Burden Inventory. *Gerontologist* 29 (6) 798-803

Noyes J (1998) A critique of studies exploring the experiences and needs of parents of children admitted to paediatric intensive care units. *Journal of Advanced Nursing* 28 1 134-141

O brien I, Duffy A, Nicholl H (2009) The impact of childhood chronic illnesses on siblings: A literature review. *British Journal of Nursing* 18 (22) 1358 – 1365

O Haver J, Moore I M, Insel KC, Reed PG, Melnyk BM, Lavoie M (2010) Parental Perceptions of Risk and Protective Factors Associated with the Adaptation of Siblings of Children with Cystic Fibrosis. *Pediatric Nursing* 36 (6) 284 - 291

Oliver P (2010) *Understanding the research process*. London. Sage

Operman S, Alant E (2003) The coping responses of the adolescent siblings of children with severe disabilities. *Disability and Rehabilitation* 25 (9) 441-454

Oxford English Dictionary (2015) Oxford. Oxford. University Press.

Packman W, Greenhalgh J, Chesterman B, Schaffer T, Fine J, Vanzutphen K, Golan R, Amylon MD (2005) Siblings of Pediatric Cancer Patients. The quantitative and qualitative nature of quality of life. *Journal of Psychosocial Oncology* 23 (1) 06. 87-108

Palmer C (1996) Information work at the boundaries of science: Linking the library services to research practices. *Library Trends* 44 (2) 165-192

Palmer A, Burns S and Bulman C eds (1994) *Reflective Practice in Nursing: Growth of the Professional Practitioner*. London: Blackwell.

Paris A., S.G. Paris (2003). Assessing Narrative Comprehension in Young Children. *Reading Research Quarterly* 38 (1): pp 36-76.

Parkin D and Stone L (2004) *Kinship and Family: An Anthropological Reader*. Oxford. Wiley-Blackwell

Piaget J (1954) *The construction of reality in the child*. New York. Basic Books.

Pillowsky T, Yirmiya N, Doppelt O, Gross Tsur V and Shalev RS (2004) Social and Emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*. 45 4 855-865

Pink, S. (2001) *Doing Visual Ethnography*, London: Sage

Pink, S. (2003) 'Interdisciplinary Agendas in Visual Research: Re-Situating Visual Anthropology', *Visual Studies*, 18(2): 179-192

Pink, S. (2004) 'Performance, Self-Representation and Narrative: Interviewing with Video', in C. Pole (ed.) *Seeing is Believing? Approaches to Visual Research*, *Studies in Qualitative Methodology*, volume 7, Oxford: Elsevier JAI, pp. 61-77

Pobi S (2007) *PALS –Getting it Right for Children and Young People. Consultations with children and young people*. National Children's Bureau

Pole, C. (ed.) (2004) *Seeing is Believing? Approaches to Visual Research*, *Studies in Qualitative Methodology*, volume 7, Oxford: Elsevier JAI

Polkinghorne (1988). *Narrative Knowing and the Human Sciences*, SUNY (State University of New York).

Porter Abbott H. (2002). *The Cambridge Introduction to Narrative*, Cambridge University Press.

Powell S.,

Postman N (1996) *The disappearance of childhood*. New York. Vintage Books.

Postman N (1983) *The disappearance of childhood*. London. W.H.Allen

Prout A (1999) *The body, childhood and society*. London. St Martins Press.

Prout A (2005) *The Future of Childhood*. Oxon. Routledge.

Prout A and James A (2007) A new paradigm for the sociology of childhood Provenance, Promise and Problems pp7-34 in James A, Prout

A (eds) *Constructing and reconstructing childhood. Contemporary issues in the Sociological study of Childhood*. London/New York. Falmer Press.

Prout A and James A (2015) A new paradigm for the sociology of childhood Provenance, Promise and Problems pp7-34 in James A, Prout A (eds) *Constructing and reconstructing childhood. Contemporary issues in the Sociological study of Childhood*. London/New York. Falmer Press

Pufall PB and Unsworth R (2004) *Rethinking Childhood*. New Jersey. Rutgers University Press

Radley A, Taylor D (2003) Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Health Research* 13 (1) 77-99

Rahm-Hallberg I (2003) Evidence based nursing, interventions and family nursing: Methodological obstacles and possibilities. *Journal of Family Nursing*. 17 424- 438

Rawson H (2009) "I'm going to be here long after you've gone" – sibling perspectives of the future. *British Journal of Learning Disabilities* 38, 225-231

Rennick J (1995) The changing profile of acute childhood illness: A need for the development of family nursing knowledge, *Journal of Advanced Nursing* 22 (2) 258-266

Ribbens J C (1994) *Mothers and Their Children. A feminist sociology of childrearing*. London. Sage

Ribbens McCarthy J and Edwards R (2011) *Key Concepts in Family Studies*. London. Sage

Richardson M J (2015) *Irish Incarnate: masculinities and intergenerational relations on Tyneside*. Thesis. Newcastle. Newcastle University.

Richardson M J (2015) Theatre as a safe space? Performing intergenerational narratives with men of Irish descent. *Social and Cultural Geography* 16 (6) 615-633

Reissman C.K. (2000) "Stigma and Everyday Resistance Practices: Childless Women in South India". *Gender and Society* 1: 127-207

Reissman C.K. (2008) *Narrative Methods for the Human Sciences*. London:Sage.

Reissman C.K. (2002) Narrative Analysis in A.M. Huberman and M.B Miles, eds. *The Qualitative Researcher's companion*. Thousand Oaks, CA. pp. 217 – 270. 2002

Reissman C.K. (2006) The ground they walk on: Photography and narrative inquiry. *The Qualitative Report*. 15 (3) 547-568

Reissman C.K. (2007) *Narrative Methods for the Human Sciences*. London. Sage.

Riessman, C.K. (1993) *Narrative Analysis*. Qualitative Research Methods Series, No. 30. Newbury Park, C.A.: Sage

Rodrigues N and Patterson J M (2007) Impact of Severity of a Child's Chronic Condition on the Functioning of Two Parent Families. *Journal of Pediatric Psychology* 32 (4) 417 – 426

Rogers R, Malancharuvil-Berkes E, Mosley M, Hui D, O'Garro Joseph (2005) Critical Discourse Analysis in Education. A review of the Literature. *Review of Educational Research* 75 (3) 365-416

Rogers A (2012) Geographies of the performing arts: Landscapes, places and cities. *Geography compass*. 6, 60-75

Rommens, J. M. *et al.* (1989) Identification of the cystic fibrosis gene: Chromosome walking and jumping. *Science* 245, 1059-1065.

Ross HS (1996) Negotiating principles of entitlement in sibling property disputes. *Developmental Psychology* 32 90-101

Ross P, Cuskelly M (2006) adjustment and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*. 31 2 77-86

Rousseau, Jean-Jacques [1762] *The Social Contract* in Bertram C (2003). *Rousseau and the social contract*. London. Routledge.

Rousseau, Jean-Jacques ([1972] 1992) *Emile*. Translated by Barbara Foxley) London. J.M.Dent & Sons.

Rowe D (2007) *My Dearest Enemy, My Dangerous Friend: Making and Breaking Sibling Bonds*. London. Routledge.

Rowe and Verkman (2013) cystic fibrosis transmembrane regulator correctors and potentiators. cold spring harbor perspectives in Medicine 1-16

Royal College of Nursing (2009) *Research ethics: RCN guidance for nurses*. [www.rcn.org.uk/ data/assets/pdf file/0010/78742/003138.pdf](http://www.rcn.org.uk/data/assets/pdf_file/0010/78742/003138.pdf)
Accessed: 20/10/12

Royal College of Paediatrics and Child Health (2015) & US *The voice of children young people and families*. RCPCH. www.rcpch.ac.uk. Accessed 13/12/15.

Royal College of Paediatrics and Child Health (2010) *Not just a phase. A guide to the participation of children and young people in health services* London. RCPCH.

Royal College of Paediatrics and Child Health (2005) *Coming out of the shadows: A strategy to promote participation of children and young people in RCHCH activity*. London. RCPCH.

Ruble DN, Boggiano AK, Feldman NS, and Loebel JH (1980) Developmental analysis of the role of social comparison in social evaluation. *Developmental Psychology*. 16, 105-115

Sackett DL, Strauss SE, Richardson WS, Rosenberg W, Haynes RB (2000) *Evidence-Based Medicine: How to practice and teach EBM, 2 nd Edition*. Edinburgh and New York. Churchill and Livingstone.

Sanders R (2004) *Sibling Relationships: Theory and Issues for Practice*. Hampshire. Palgrave Macmillan.

Sartain SA, Clarke CL, Heyman R (2000) Hearing the voices of children with chronic illness. *Journal of Advanced Nursing* 32 (4) 913 -923

Schatz M and Steiner-Loffler U (1998) Pupils using photographs in school self-evaluation, in J Prosser (ed) *Image based research: A Sourcebook for Qualitative Researchers* pp235-51. London: Falmer Press

Scourfield J, Dicks B, Drakeford M and Davies A (2006) *Children, Place and Identity. Nation and locality in middle childhood*. London. Routledge

Scourfield, J., Dicks, B., Holland, S., Drakeford, M. and Davies, A. (2006) The significance of place in middle childhood: qualitative research from Wales. *British Journal of Sociology* . 57, 4: 577-595.

Schon D (1983) *The Reflective Practitioner: Towards a new design for teaching in the professions*. San-Fransisco. Jossey-Bass.

Schultz JA (2004) *Knowledge of Childhood in Heywood. A History of childhood. Children and Childhood*. (Themes in History). Cambridge. Polity

Seale C (2005) 'Using Computers to Analyse Qualitative Data', in D. Silverman *Doing Qualitative Research*, 2nd edition, London: Sage, pp. 188-208

Searle JR (1969) *Speech Acts: An essay in the philosophy of language*.

Cambridge. Cambridge University Press.

Selman RL (1976) *Moral development and behavior - social-cognitive understanding: A guide to educational and clinical practice*. New York. Holt, Rinehart, & Winston.

Schank R.C. (1990). *Tell Me a Story: Narrative and Intelligence*, Northwestern University Press.

Simms S (2002) Sibling support in childhood cancer. *Paediatric Nursing* 14 (7) 20 – 22

Sharpe D and Rossiter L (2002) Siblings of Children With a Chronic Illness: A Meta Analysis. *Journal of Pediatric Psychology*. 27 (8) 669-710

Shaw C, Braidy M.L, Davey C (2011) *Guidelines for research with children and young people*. Research centre. London. National Children's Bureau.

Shelton TL, Jepson ES & Johnson BH (1987) *Family-Centred Care for Children With Special Health Care Needs*. Washington DC: Association for the Care of Children's Health.

Shields L (2010) Questioning family centred care. *Journal of Clinical Nursing*. 19 (17/18) 2629-38

Shields L, Aggarwal S, Chadha P, Kalia S, Richardson S, winterbottom L (2009) Perceptions of family centred care: A UK pilot study of the Shields and Tanner questionnaires. *Neonatal, Paediatric and Child Health Nursing* 12 (2) 25 -29

Shields L (2007) Family-Centered Care in the perioperative area: An international perspective. *Aorn Journal*. 85 (5) 893-902

Shields L, Pratt J, Davis L, Hunter J. (2007) Family-centred care for children in hospital. *Cochrane Database of Systematic Reviews*, Issue 1. Art. No.: CD004811. DOI: 10.1002/14651858.CD004811.pub2

Shields L, Pratt J and Hunter J (2005) Family centred care: a review of qualitative studies. *Journal of Clinical Nursing*. 15, 1317–1323

Shields L, Hunter J and Hall J (2004) parents and staffs perceptions of parental needs during a child's admission to hospital: An English Perspective. *Journal of Child Health Care: for professionals working with children in the hospital and in the community* 8: (1) 9 – 30

Shields, L., and J. Nixon (1998) *I want my Mummy - changes in the care of children in hospital*. *Collegian* 5 (2):16-19.

Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing*

Talk, Text and Interaction, 2nd edition, London: Sage

Silverman, David (2005) *Doing Qualitative Research*, 2nd edition, London: Sage

Simms S (2002) Sibling support in childhood cancer. *Paediatric Nursing* 14 (7) 20 – 22

Smith F (1995) *Children's Nursing in Practice: The Nottingham Model*. Oxford. Blackwell Science.

Smith L and Coleman V (2010) *Child and family centred care. Concept, Theory and Practice*. (2nd Edition). Basingstoke. Palgrave.

Smith J, Swallow V, Coyne I (2015) Involving Patients in Managing Their Child's Long-Term Condition. A concept synthesis of Family Centered Care and Partnership in care. *Journal of Pediatric Nursing*, 30 143-159

Smith L, Coleman V and Bradshaw M (2002) Family-centred care: a practice continuum. In: L Smith, V, Coleman and M Bradshaw (eds) *Family Centred Care Concept Theory and Practice*. Basingstoke: Palgrave.

Smith J, Swallow V, Coyne I (2015) Involving parents in managing their children's long-term condition - A concept synthesis of family centered care and partnership in care. *Journal of Pediatric Nursing* 30, 143-159

Sloper P (2000) Experiences and support needs of siblings of children with cancer. *Health and social care in the community* 8 (5) 298-306

Spradley, J (1979) *The Ethnographic Interview*, Holt, Rinehart and Winston, New York.

Spradley, J (1980) *Participant Observation*, Harcourt College Publishers, Fort Worth.

Spencer L, Ritchie J, Lewis J and Dillon L (2003) *Quality in Qualitative Evaluation: A framework for assessing research evidence. A quality framework*. Government Chief Social Researchers Office: London: Cabinet Office.

Spilkin A and Ballantyne A (2007) Behaviour in children with a chronic illness: A descriptive study of child characteristics, family adjustment, and school issues in children with cystinosis. *Families, Systems and Health* 25 (1) 68 -84

Stark V (2007) *My sister, myself: Understanding the sibling relationship that shapes our lives, our loves, ourselves*. New York. Mcgraw-Hill

Stoneman Z and Brody GH (1993) Sibling temperaments, conflict, warmth and role asymmetry. *Child Development*. 64 (6) 1786-800

Stocker C and Dunn J (1990) Sibling relationships in childhood: Links with friendships and peer relationships. *British Journal of Developmental psychology*. 8 (3) 227-224

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage

Swallow V M and Jacoby A (2001) Mothers' evolving relationships with doctors and nurses during the chronic illness trajectory. *Journal of Advanced Nursing*, 36, 755-764

Swallow VM, Macfayden A, Santacroce S J and Lambert H (2012) Fathers contributions to the management of their child's long-term medical conditions: A narrative review of the literature. *Health Expectations* 15 157-175

The Cystic Fibrosis Center at Stanford (2015). Education. Genetics. www.med.stanford.edu. Accessed 1/12/15.

Thomson P (2008) *Doing visual research with children and young people*. Oxon. Routledge.

Thompson N (2012) The family in the social context in Adams R (2012) *Working with children and families. Knowledge and contexts for practice*. Basingstoke. Palgrave Macmillan. Chapter 8. 91-98

Titchen A, Higgs J (2000) *Clinical reasoning in the health professions* Oxford. Butterworth Heinemann

Tomlinson PS, Thomlinson E, Peden McAlpine C, Kirschbaum M (2002) Clinical innovation for promoting family care in paediatric intensive care: demonstration role modeling and reflective practice. *Journal of Advanced Nursing*. 38 2 161-170

Turk J (1964) Impact of cystic fibrosis on family functioning. *Pediatrics*. American Academy of Pediatrics. 34 (1) 67-71

Twycross A, Gibson F and Coad J (2008) Guidance on seeking agreement to participate in research from young children. *Paediatric Nursing*. 20 (6) 14 - 18

Tuan YF (2001) *Space and Place. The Perspective of Experience*. London, Minneapolis. University of Minnesota Press.

Turner M. (2009) *University policy and guidance health and safety in fieldwork*. Safety Health and Environment Committee. Cardiff. Cardiff University.

UK Cystic Fibrosis Registry (2015) *Cystic Fibrosis strength in numbers. 2014 Annual Data Report*. London. Cystic Fibrosis Trust.

United Nations, Office of the High Commissioner for Human Rights convention rights of the child (1989). *Convention on the Rights of the Child*. Geneva. UN

Valentine F and Lowes L (2007) *Nursing care of children and young people with chronic illness*. Oxford. Blackwell publishing.

Van Riper M (2003) *The sibling experience of living with a childhood chronic illness and disability*. Annual Review of Nursing Research. 21, 279-302

Vermaes IPR, Van Susante AMJ, Van Bakel HJA (2001) Psychological Functioning of Siblings in Families of Children with Chronic Health Conditions. A Meta-Analysis. *Journal of Paediatric Psychology*. 37 (2) 166. 1-19

Vertex Pharmaceuticals (2015) *Highlights of prescribing information*. Kalydeco. 1-16. Pi.vrtx.com accessed 1/12/2015

Vogt PW (2005). *Purposive Sample*. Dictionary of statistics and methodology. London. Sage.

Volling BL, Elins JL (1998) Family relationships and children's emotional adjustment as correlates of maternal and paternal differential treatment: A replication with toddler and preschool siblings. *Child Development*. 69 (6) 1640-1656

Vygotsky L.S (1978) *Mind in Society. The development of Higher Psychological Processes*. Edited by Cole M, John-Steiner V, Sribner S and Souberman E. Cambridge. Harvard University Press.

Wales Assembly Government (2011) *Voices of Children and Young People in Wales Study: A qualitative study of Wellbeing among children and young people under 25 years old –bases study around UN conventions rights of the child*. Cardiff. Wales Assembly Government.

Wales Assembly Government (2009) *Research Governance Framework for Health and Social Care in Wales*. Second Edition. Cardiff. Wales Assembly Government.

Wales Assembly Government (2002) *Children and Young People: Rights to Action*. Cardiff. Wales Assembly Government

Wales Assembly Government (2007) *Children and Young People's Policy*. Cardiff. Wales Assembly Government.

Wales Assembly Government (2004) *National Service Framework for Children, Young People and Maternity Services in Wales*. Cardiff. Wales Assembly Government.

Wahab AA, Taj-Aldeen SJ, Hagen F, Diophode S, Saadoon A, Meis JF, Klaasen CH (2014) Genotype diversity of *Pseudomonas aeruginosa* in cystic fibrosis siblings in Qatar using AFLP fingerprinting. *European Journal of Clinical Microbiology of Infectious Disease*. 33:265-271

Wainwright C E, Elborn J S, Ramsey B W, Marigowda G, Huang X, Cipolli M, Colombo C, Davies JC, De Boeck K, Flume PA, Konstan MW, McColley S A, McCoy K, McKone E F, Munck A, Ratjen F, Rowe S M, Waltz D, Boyle M P (2015) Lumacaftor – Ivacaftor in Patients with Cystic Fibrosis, Homozygous for Phe508del CFTR. *The New England Journal of Medicine* 373: 220-231.

Waite- Jones J, Madill A (2008a) Concealed Concern: father's experiences of having a child with juvenile idiopathic arthritis. *Psychology and health* 23 (5) 585 – 601

Waite-jones and Madill (2008b) Amplified ambivalence: Having a sibling with juvenile idiopathic arthritis. *Psychology and health* 23(4) 477-492

Wallis C (2007) Diagnostic aspects of cystic fibrosis. In Hodson M, Geddes D and Bush A (2007) *Cystic Fibrosis*. Third Edition. London. Hodder Arnold.

Waller, D. and Gilroy, A. (eds.) (1992) *Art Therapy: A Handbook*, Buckingham: Open University Press

Walther L (1979) The Invention of Childhood in Victorian autobiography. In Landan GP (1979) *Approaches to Victorian Autobiography*. Athens OH, Ohio University Press.

Ward M.R.M (2013) *The performance of Young Working-Class Masculinities in the South Wales Valleys*. Unpublished Thesis. Cardiff University.

Ward C, Glass N, Ford R (2014) Care in the home for seriously ill children with complex needs: A narrative literature review. *Journal of Child Healthcare*. 1-8

Wartovsky M (1981) The child's construction and the worlds construction of the child from historical epistemology to historical psychology: In F kessel and A seigal eds, *The child and other cultural interventions*, New York: Praeger.

Watts L (2009) Managing self in role: using multiple methodologies to explore self construction and self governance.p 215 – 239 in Clarke S and Hoggett 2009 *researching beneath the surface. Psycho social research methods in practice*. Great Britain. Karnac books.

Watson, D., Abbott, D. and Townsley, R. (2006) Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services. *Child: care, health and development* , 33(1), 90-95

Weissman M M, Feder A, Pillowsky DJ (2004) Depressed mothers coming to primary care. Maternal reports of problems with their children. *Journal of affective disorders* 78 2 93-100

Wenstromm IL, Isberg PE, Wirtberg I and Ryden O (2011) From children to young adults: Cystic Fibrosis and siblingship A longitudinal study. *Acta Paediatrica* 100 (7) 1048-1053

Whiting L (2015) Reflecting on the use of photo elicitation with children. *Nurse Researcher*, 22 (3) 13-17

Wiehe M and Arndt K (2010) Cystic Fibrosis: A Systems Review. *AANA Journal* 78 (3) 246-251

Wilkins KL and Woodgate RL (2005) A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. *Journal of Pediatric Oncology Nursing*. 22 (6) 305-319

Wilkins KL and Woodgate RL (2007a) An interruption in family life: Siblings' lived experience as they transition through the pediatric bone marrow transplant trajectory. *Oncology Nursing Forum* 34 (2) E28 – E35

Wilkins KL and Woodgate RL (2007b) Supporting siblings through the pediatric bone marrow transplant (BMT) trajectory: Perspectives of siblings of BMT. *Cancer Nursing*, 30 (5) E29 – E34

Wilkinson, H. (1999) 'The Thatcher Legacy: Power Feminism and the Birth of Girl Power', in N. Walter (ed.) *On the Move: Feminism for a New Generation*, London: Virago, pp. 27-47

Williams, B. (2002) 'Using Collage Art Work as a Common Medium for Communication in Interprofessional Care', *Journal of Interprofessional*

Care, 16(1): 53-58

Williams PD, Ridder EL, Setter RK (2009) Pediatric chronic illness cancer, cystic fibrosis effects on well siblings: Parents' voices. *Issues in Comprehensive Pediatric Nursing* 32 (2) 94-113

Williams, T., Wetton, N. M. and Moon, A. (1989a) *A Picture of Health*, London: Health Education Authority

Williams, T., Wetton, N. M. and Moon, A. (1989b) *A Way In*, London: Health Education Authority

Willis, P. (1990) *Common Culture: Symbolic Work at Play in the Everyday Cultures of the Young*, Milton Keynes: Open University Press

Winn M (1983) *Children Without Childhood*. New York. Pantheon Books.

Wolcott, H. (1994) *Transforming Qualitative Data: Description, Analysis and Interpretation*, Sage Publications, Thousand Oaks, California.

Wong MG, Heriot SA (2008) Parents of children with cystic fibrosis: How they hope, cope and despair. *Child: Care, Health and Development*. 34 (3) 344-354

Woodgate RL (2006) Siblings experience with childhood cancer – A different way of being with the family. *Cancer nursing* 29(5) 406 – 414

Wyness M (2012) *Childhood and Society*. Second Edition. Basingstoke. Palgrave.

Yardley, L. (2000). Dilemmas in Qualitative Health Research. *Psychology and Health* 15:215-228.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J A Smith *Qualitative psychology: A Practical Guide to Research Methods*. 2nd edition. London: Sage Publications Ltd.

Zwaan R.A. (1999). Five Dimensions of Narrative Comprehension: The Event Indexing Model, in *Narrative Comprehension, Causality and Coherence*, edited by S. Goldman, A. C. Graesser and K. Wiener-Hastings. LEA: pp 93-110.

APPENDIX

APPENDIX 1

LITERATURE SEARCH STRATEGY AND TABLE

The literature search was initiated in the earlier months of 2011 prior to commencing this PhD study in October 2011. The search was commenced to identify gaps in the literature in relation to my interest and concern for siblings living in a family with a chronically ill child. An interest that had resulted from teaching students the subject, family centered care in children's nursing practice. I wanted to increase my teaching repertoire to be able to inform students of the wider picture of caring for children and their families, and so I raised my ideas with Professor Daniel Kelly and Dr Katie Featherstone, who became my supervisors, then my search of the literature began. The literature that was accessed during these preliminary months enabled my ideas to expand and my research questions to be formulated and incorporated into a research protocol. I continued to access further literature from October 2011 to October 2013 whereby I expanded my search terms, accessed different search databases to broaden my review. Towards the latter end of conducting my fieldwork and during analysis the data the literature was revisited between the months of October 2014 and October 2015 to ensure an updated review and to inform the data analysis process.

PRELIMINARY LITERATURE SEARCH

January 2011 to October 2011

The following key databases were used to access the information: American psychological associated database (Psych info), Cumulative Index for Nursing and Allied health Literature (CINAHL), Cochrane library, EMBASE, EBSCO host.

KEY SEARCH TERMS USED

Sibling/siblings

Brother

Sister

Chronic illness

Family

Child/childhood/children

Family centred care

The search frame was set to access data that had been published within the 10-year time frame span between 2001 and 2011. However, to enable the exploration of the historical evolution of key concepts, data was also accessed and used outside of this time frame.

SEARCH INCLUSION CRITERIA

The search inclusion criteria included accessing articles that were in the English language only and that had been peer reviewed for its content. Articles accessed were primary research, literature reviews, meta-analysis and systematic reviews. Articles focused on were those relating to siblings and families living with a brother or sister with chronic illness, articles relating to family centred care, family and childhood.

SEARCH EXCLUSION CRITERIA

The search excluded articles that were not written in the English language, articles that had not been peer reviewed. Articles were excluded that related to siblings that had died and where the focus was related to adult siblings.

LITERATURE SEARCH OCTOBER 2011 TO OCTOBER 2013

Between the months stated above the literature search was expanded to incorporate the following additional databases in conjunction with the ones previously mentioned; Applied Social Sciences Index and Abstracts (ASSIA), Scopus, Google scholar, Orca and Pubmed. Relevant books and

thesis were also accessed via Cardiff University Library search as well as hand searched in three Cardiff University libraries; Bute library, Arts and Social Science library and The Health Library.

ADDITIONAL SEARCH TERMS

Search terms were also expanded to include the word 'and' as well as address new search criteria, which can be viewed below.

Sibling relationship

Brother and Sister

Sibling and chronic illness

Family and chronic illness

Cystic fibrosis

Cystic fibrosis and family

Cystic fibrosis and sibling

Cystic Fibrosis Transmembrane Conductance Regulator (CFTR)

These terms were added as a result of the gap identified in the preliminary review that informed my focus of siblings living with a brother/sister with cystic fibrosis. Due to the limited data available in relation to child siblings with a brother or sister with cystic fibrosis, my data search fell outside the 10-year time frame and accessed more historical studies as well as a seminal piece of work.

ADDITIONAL INCLUSIONS /EXCLUSIONS

Added to my inclusion criteria were child siblings of cystic fibrosis, Family with a child with cystic fibrosis and I excluded studies of adult siblings of adults with cystic fibrosis as well as death of a sibling with cystic fibrosis as this was not the focus for my study.

FINAL SEARCH

Between October 2014 and November 2015 the search terms mentioned above were reapplied using all of the databases outlined above along with the inclusion and exclusion criteria. Dates searched were between 2013

and 2015 to generate up to date literature to inform the study. New data hav been applied to the work.

Literature Search table

All article titles are listed in full in the reference list

Author	Topic	Method/sample	Main Findings
Alderfer et al. (2010)	Impact of childhood cancer on siblings	Systematic review n=65 papers	Implications in relation to the sibling experience. No differentiation between siblings own view and that of proxy or mixed informants
Barrera et al. (2004)	Social support and psychological adjustment in siblings of children with cancer	Quantitative research study Sibling and parent questionnaires Sibling n=47 Control n=25 Parents n=24	Positive psychological adjustment and less behavioural problems were reported with good psychological support
Bellin and Kovacs (2006)	Experience of healthy siblings	Literature Review	Sibling experience of loss. Sibling social competence.
Bellin, Kovacs and Savin (2008)	Risk and protection influences in the lives of youths with spina bifida	Quantitative n=155 brothers and sisters Questionnaire	Adaptive coping mechanisms can be influenced by spirituality, family cohesiveness and supportive peer friendships
Bransetter (2008)	Families of children with chronic illness	Qualitative phase/RCT phase. Semi-structured interviews n=30 parent/sibling dyads and others	Families expressed the need to stay together as a family. Communication opportunities need to be increased to help families to stay connected, to

			help them develop a new normalcy. Suggests more effective communication promotes adaptation
Essen and Enskar (2003)	Parent and nurse perceptions about what aspects of care and assistance are important for siblings of cancer	Qualitative Cross sectional/descriptive n=97 parents and n=34 nurses Semi-structured interviews	Important aspects of care for siblings include participation, receiving information and psychosocial care
Gursky (2007)	The effect of educational interventions on hospitalized children	Quantitative Experimental design n=50 siblings n=25 experimental group n=25 control group	Siblings of chronically ill children can experience significant emotional and behavioural changes, educational intervention can reduce the stress response of hospitalisation
Hamama et al. (2008)	Healthy children's responses to a siblings cancer and its consequences	Quantitative n=53 boys and 47 girls Psychometric scoring inventories	There is a correlation between healthy siblings and cancer duress responses.
Hastings (2003)	Siblings of children with autism	Quantitative research study Maternal questionnaires n=20 mothers	Siblings experienced less behavioural, social and peer problems
Hollidge (2001)	Psychological adjustment of siblings to a child with diabetes	Quantitative Standardised tests/semi-structured interview n=28 well sibling	Well siblings rate themselves as being unhappier than their mothers about their sibling's diabetes. Guilt was the most prevalent

			affect experienced by well siblings Suggests siblings can master their external world but internalised emotional distress
Houtzager (2005)	Quality of life coping and previous functioning in siblings of children with cancer	Quantitative n=83 sibling from 53 families	Siblings reported impaired cognitive and emotional quality of life. Older siblings reported more negative emotions than younger ones.
Hughes (2007)	Survey of parent attitudes to family centred care	43 parents and 28 nurse participants	Parents unsure of what was expected of their role. Parents perceived nurses to be busy and could not meet their child's needs
Kaminsky and Dewey (2002)	Psychosocial adjustment in siblings of children with autism	Quantitative study Sibling and parents Questionnaire n= 90 siblings n=90 parents	Siblings of children with autism are well adjusted
Kao, Plante and Lobato (2009)	The use of the impact on sibling scale with families of children with chronic illness and developmental disability	Quantitative research n=122 parents of siblings age 4-13 years old	There was a higher scoring on the impact on sibling scale in the chronic illness group than with autism or developmental disability.
Knecht (2015)	The perspective of siblings of children with chronic illness	Literature review	Concludes that the sibling voice remains marginalised
Labay and Walco (2004)	Empathy and psychological adjustment in siblings of	Quantitative research study n=20 families 29 siblings and 14	There is a positive correlation between empathy

	children with cancer.	children with cancer Sibling and parent questionnaires	and sibling adaptation. Siblings do not exhibit behavioural problems. Cancer knowledge not related to adjustment. If a child is close in birth order then less positive adjustment
Mandleco and Webb (2015)	Sibling perceptions of living with a young person with Down's Syndrome or autism spectrum disorder	Literature review	Suggests that siblings need to be provided with knowledge about the chronically ill child's condition.
Mulroy et al. (2008)	The impact of having a sibling with an intellectual disability	Qualitative n=186 parents of Down's Syndrome n=141 parents of Rett's Syndrome Open-ended questions	Parents report advantages and disadvantages for siblings living with children with both conditions
Murray (1999)	Effect of childhood cancer on healthy sibling	Literature review	Suggests that the sole sibling voice not highlighted or differentiated between other informants
Murray (2000)	Adjustment difficulties in siblings of children with cancer	Literature Review	Suggests that information and support needs to be provided for siblings of cancer to reduce adjustment difficulties and promote adaptive coping
O'brien (2009)	Impact of childhood illness on siblings	Literature review	Suggests that the sibling voice is not highlighted /differentiated
Operman and Alant	Coping responses of	Qualitative Open-ended structured	Siblings report minimised

(2003)	adolescent siblings of children with disabilities	interviews n=19 siblings	interaction within the family and a reluctance to express feelings Insufficient information is provided regarding their siblings disability
Packman et al. (2004)	Siblings with cancer	Quantitative research study Questionnaires pre and post intervention n=77	Sibling stress and anxiety was reduced by attending a summer camp also, quality of life was increased
Pillowsky et al. (2004)	Social and emotional adjustment of siblings with children with autism	Quantitative research study Questionnaires Three sibling groups n=30 n=30 n=28	Siblings of children with autism are well adjusted and display enhanced empathy towards their brother or sister.
Ross and Cuskelly (2006)	Siblings of children with autism	Quantitative Sibling and parent questionnaire n=25 siblings n=25 mothers	Siblings used positive thought or wishful thinking to control their emotions
Sartain (2000)	Hearing the voices of children with chronic illness	Qualitative n=7 families Semi-structured interviews	Children are capable of giving an opinion and their views can add to the childhood narrative
Sharpe and Rossiter (2002)	Siblings of children with a chronic illness	Meta-analysis n=51 papers	Parental reports of siblings living with a child with chronic illness were more negative than child self reports
Sloper (2000)	Parent and sibling experience living with a child with cancer	Qualitative Separate interviews with parents and siblings n=133 families	Siblings encountered losses including companionship, security and loss

			of certainty Siblings reported gains in terms of closer family relationship and increased independence
Waite-Jones and Maddill (2008)	Amplified ambivalence. Having a sibling with juvenile arthritis	Qualitative study n=8 families Interviews	Vulnerability of siblings during adolescence. Siblings experience amplified ambivalence. There is a need for extended family support
Wilkins and Woodgate (2005)	The childhood cancer experience from the perspective of siblings	Qualitative review	Suggested the need to recognise the importance of to giving siblings their voice
Wilkins and Woodgate (2007)	Siblings lived experience as they transition through the bone marrow trajectory	Qualitative n=8 siblings Semi-structured open ended interviews	Siblings cope with good days and bad days Siblings need to feel part of the family and have a sense of belonging
Williams (1997)	The effects of paediatric chronic illness on siblings living at home with an ill child	Literature review	Siblings sole view not highlighted
Woodgate (2006)	Siblings' experiences with childhood cancer	Part of a larger qualitative study n=30 siblings open ended interviews	Siblings experienced a different way of being with their family Siblings experienced a loss of self and loss of family life as they new it Committed to keeping the

			family together All siblings expressed their feeling of sadness
Van Riper (2003)	Nursing research on the sibling experience of living in a family that includes a child with a disability or chronic illness	Integrative review n= 40 papers	Highlighted emotional deprivation of the sibling, feelings of sadness and sorrow
Vermaes et al. (2012)	Psychological functioning of siblings in families of children with chronic health conditions	A Meta-Analysis n=36 studies including parents and 25 studies with siblings as respondents	A small but significant negative effect of chronic illness on the siblings including internalising and externalising problems. Older siblings and siblings of children with life threatening or complex illness were more at risk for psychological problems

APPENDIX 2: PUBLICATION AND DISSEMINATION PLAN

A fundamental aspect of undertaking the PhD research training is to disseminate knowledge gained, so that information can be shared and accessed by others to help advance professional practice. I have a track record of being involved in practice developments at policy and training

levels, and dissemination will be at local, national and international level. To date dissemination has been progressive and ongoing throughout the project in terms of presenting at conferences and in submitting poster presentations as can be viewed in Appendix 2.

It is my intention to publish the work that is presented in my thesis and to focus on the publication of 5 key articles in relevant, targeted, peer review journals that have International / National status

Suggested articles and target journals for publication

Article 1. A discussion Paper in relation to the use of dramaturgy in exploring the worlds of siblings in the context of cystic fibrosis

Target Journal: Journal of Advanced Nursing

Article 2: Methodological challenges: The creative bricolage and the narrative performance of the sibling voice

Target Journal: Qualitative Research / International Journal of Social Research

Article 3: The positional status of child siblings living in the context of cystic fibrosis

Target Journal: Journal of child Health care / or Child: care, health and development

Article 4: Sugar and Spice and All things nice: The importance of being a good sibling when living with a child with cystic fibrosis

Target Journal: Journal of child Health care / or Child: care, health and development

Article 5: The emotional labour of living with a sibling with cystic fibrosis: Child performance narratives.

Target Journal: Journal of Child Health Care / or Child: care, health and development

Further dissemination

Local Level

All of the children and their families will be notified of the key outcomes of the study and the children will be awarded with a certificate for participating in the study. I will be visiting each family on completion of the thesis, to award the certificate and provide a child friendly written account of a summary of the findings to each sibling. A separate information/ feedback sheet will be given to the parents of the children.

Staff at the cystic fibrosis clinic will also be notified of the study findings and will be provided with a key summary of information

Information will be shared/presented in local Cardiff University Research networks of which I am a member of and these networks include:

1. The Child and Youth Research Network
2. The Family, Identity and Gender Research Network
3. Creative Cardiff Research Network

Information will be disseminated through my learning and teaching activities with children/young people student nurses. I plan to not only incorporate the study findings, but also to incorporate creativity and drama in the classroom to enhance student learning.

National Level

Information will be shared with the Cystic Fibrosis Trust

A report has been submitted to the Florence Nightingale Foundation

A report has been submitted to the Royal College of Nursing

I intend to present at a National conference relating to child health / research in addition to the presentations that I have already undertaken (see appendix 2)

International Level

I intend to submit an abstract to present research findings at an international Cystic Fibrosis Conference

I intend to submit an abstract to present research findings at an international child health/ family conference

(See appendix 2 for my previous International dissemination work)

APPENDIX 3

PhD Study presentations given and Awards received.

Conference / research fellowship presentations

Hodges AS (2015) Siblings talking the visual: Narrative accounts of children's everyday lives. Living with a brother or sister with cystic fibrosis.

Royal College of Nursing International conference. Nottingham.

Hodges AS (2015) Talking Pictures: Siblings accounts of living with a child with cystic fibrosis. Undergraduate Research Symposium, Cardiff University. Cardiff.

Hodges AS (2014) Sibling Narratives: Talking the visual. Family Life and Cystic Fibrosis. Brocher Foundation, Hermance, Switzerland. (Invited speaker to present to representatives from WHO, UN, The Red Cross, Swiss Health, Brocher Foundation Staff and International Research scholars).

Hodges AS (2014) Creating Pictures: Talking the visual: Siblings of children with cystic fibrosis. Cardiff University. Post-graduate symposium. Cardiff.

Hodges AS (2012) Family centered care and the sibling: Ideology versus reality. Informing the need for a research project. Cardiff University Postgraduate Symposium. Cardiff.

Poster Presentations

Hodges AS (2014) Siblings, Family and cystic fibrosis. Florence Nightingale Foundation. International Conference. London.

Hodges AS (2014) The 'Listen Hear' Project: Using Visual Elicitation and Narrative Inquiry to Explore the Family Centered Care Experience of Siblings in the Cystic Fibrosis Trajectory. 6 TH international Conference on patient and family centred care / Institute for patient and family centred care. Vancouver, Canada .

Hodges AS (2011) Hearing the views of well siblings of chronically ill children: Choice and Voice; Informing nursing care. Cardiff University post graduate research symposium. Cardiff.

AWARDS RECEIVED

1. Royal College of Nursing Professional Bursary Award (2015)
Awarded £5000
2. Cardiff University Student Alumni Award (2014) Awarded £450
3. Florence Nightingale Research Scholarship Award – The Band Charitable Trust (2014 – 2015) Awarded £1995
4. Florence Nightingale Research Scholarship Award – The General Nursing Council (2013 – 2014) Awarded £1950
5. Florence Nightingale Research Scholarship Award – The Band Charitable Trust (2012 – 2013) Awarded £1922
6. Brocher Foundation Visiting Researcher Award (2014) to spend one month as a visiting researcher at The Brocher Foundation, Hermance, Switzerland.

APPENDIX 4



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

R&D
RESEARCH & DEVELOPMENT
Abertawe Bro Morgannwg University Health Board

Dyddiad/Date: 18th March 2013

Miss Amie Hodges
Cardiff University
Cardiff School of Nursing & Midwifery Studies
Room 501, 5th Floor, Eastgate House,
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☎ 01792 704056
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✉ Jemma.Hughes@wales.nhs.uk
✉ Abm.rd@wales.nhs.uk

Dear Miss Hodges

Re: The 'Listen Hear' project
IRAS Ref: 121148
Sponsor: ABMU Health Board

Thank you for submitting your proposal to us for approval for the above named study to be carried out within our Health Board. The attached listed documents were reviewed.

Health Board Governance checks have been completed and passed. Please accept this letter as confirmation of local Health Board approval.

As part of Research Governance, you are required to:

1. Adhere to the protocol approved and inform the R&D office of any changes (including changes to the end date of the project) and ensure any changes are reported to the Research Ethics Committee(s), for review/approval.
2. Inform the R&D office of any local adverse/serious events that may occur, whilst also reporting these according to the sponsor's protocol and procedures.
3. Complete any interim and final reports requested by the R&D office. If sponsored by this Health Board, you will be asked by the Joint Scientific Review Committee to complete a 6 monthly progress report along with your final report at study completion.
4. Ensure that your research complies with any relevant regulatory requirements and legislation relating to: Clinical Trials, Data Protection Act 1998, Health & Safety, Caldicott Guidelines, the use of Human Tissue for research purposes, Mental Capacity and ICH Good Clinical Practice (GCP).
5. Ensure that all training courses requested by the Sponsor are completed by all relevant members of the research team before any research activity is carried out. All research staff undertaking clinical trials of an investigational medicinal product (CTIMPs) must be GCP trained, and should continue to update their GCP training every 2 years. Copies of GCP certificates should be filed in the Trial Site File, with a copy forwarded to the R&D Department.
6. Ensure the research is undertaken in compliance with all Health Board R&D Standard Operating Procedures (SOPs). The latest versions of all SOPs can be obtained by contacting the R&D Department.

NISCHR Clinical Research Portfolio Studies

If your study has been adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of our permission that the Chief Investigator uploads local recruitment data onto the portfolio database.

Bwrdd Iechyd ABM yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Abertawe Bro Morgannwg
ABM University Health Board is the operational name of Abertawe Bro Morgannwg University Local Health Board
Pencadlys ABM / ABM Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR. Ffon / Tel: (01639) 683344
www.abm.wales.nhs.uk

Reda Ref: 121148

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For more information on the process of uploading recruitment data please look at the following link:
<http://www.crncc.nihr.ac.uk/aboutus/processes/portfolio/precruitment>

Uploading of recruitment data will enable NISCHR to monitor research activity within Health Boards, resulting in NHS R&D allocations to be driven by activity.

To apply for your study to be adopted onto the NISCHR CRP, details can be found at:
<http://www.wales.nhs.uk>

For more information and advice on the NISCHR Clinical Research Portfolio please email:
portfolio@wales.nhs.uk

Should you wish to extend your study to other NHS organisations you must obtain the approval of all NHS bodies concerned. If the study is sponsored by ABMU Health Board you must notify the R&D Office of your intention to open the study in other sites.

Amendments to the Study

Any changes made to the study after the issue of this letter will be treated as an amendment. Amendments can be 'substantial' or 'non-substantial' and although you might not need Ethical approval for non-substantial amendments you will be required to submit the amendment for R&D approval to the below e-mail address.

All study amendments should be submitted along with all backing documentation to NISCHR PCU via e-mail, NISCHR.PCU.ALLwales@wales.nhs.uk

Indemnity Arrangements

The Sponsor indemnifies and holds harmless ABM University Health Board, its employees and agents for any harm caused by negligence on behalf of the Sponsor, including any harm caused to participants by the administration of the investigational product. However, please note that the Sponsor will not indemnify ABM University Health Board for any harm caused by negligence on behalf of the research team or other individual or agent.

Researchers employed by ABM University Health Board, including those holding Honorary Contract status are indemnified against actions for negligent harm via standard arrangements with Welsh Risk Pool (WRP). Provision for 'no-fault' compensation is limited under the scheme and is only available on an ex gratia, discretionary basis where the Sponsor is a NHS Organisation.

ABM University Health Board reserves the right to suspend approval of any research study where deviation from appropriate RG & GCP standards is uncovered.

May I take this opportunity to wish you well in undertaking the research. We will write to you in the future to request updates on the progress of the research and look forward to receiving outcomes of the study.

Yours sincerely,



Professor SC Bain
Assistant Medical Director (R&D)
ABMU Health Board
Enc: List of SSI and R&D documents submitted

Bwrdd Iechyd ABM yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Abertawe Bro Morgannwg
ABM University Health Board is the operational name of Abertawe Bro Morgannwg University Local Health Board
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www.abm.wales.nhs.uk

Reda Ref: 121148

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Re: The 'Listen Hear' project
IRAS Ref: 121148
Sponsor: ABMU Health Board

SSI Documents Submitted

Document:	Subtitle:	Version:
Other (please specify)	Dr Evans authorisation to participate as Local Collaborator	
Site-Specific Information form checklist	ABM UHB - Singleton Hospital	
Site-Specific Information Form (signed/authorised pdf or hard copy)	ABM UHB: Singleton Hospital not signed	

APPENDIX 5: RRESC

Cardiff School of Nursing and Midwifery Studies
Head of School and Dean Professor Sheila Hunt

Ysgol Astudiaethau Nyrsio a Bydwreigiaeth Caerdydd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



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11 January 2013

Amie Hodges
SONMS

Dear Amie

Re: The 'listen hear' project: An exploration of the family centred experiences of the sibling in the chronic illness trajectory

Thank you for submitting your proposal to the SONMS Research Review and Ethics Screening Committee for:

- scientific review
- ethics screening;

The Committee has now had the opportunity to review your proposal, and is happy to approve your plans, please see helpful comments below.

Please remember that this committee (RRESC) is *not* a research ethics committee (REC), and is therefore not able to give you a favourable ethics opinion. In the view of RRESC your proposal will now need to be submitted for approval through NHS research governance and ethics review procedures. Further information can be found in the 'Research Ethics Guidance for Staff and Students' document, which can be downloaded from the School's Peer Review and Ethics website [<http://www.cardiff.ac.uk/sonms/research/peerreview/index.html>]. Please note that if your project is then classified as 'not research' within the NHS (eg, if it is described and treated as a 'service evaluation'), *but* that you are presenting it as 'research' in other contexts (eg, for academic award purposes) then you should submit your project for approval through the School REC. Information on the School REC is also available on the School's Peer Review and Ethics website (URL given above).

We wish you well with your project.

Yours sincerely

Rosemary Williams
EO: Research Administration

Committee Comments

It gives us great pleasure to review the work of a PhD student at Cardiff and witness the quality of the research being proposed. The work certainly meets the standard of research that is expected in SONMS.

The proposal is well-presented, detailed and comprehensive.

Some points to think about:

Both research questions need a little re-wording to make sure they are absolutely clear.

Sample size – how was the figure of 10 arrived at? There must be some justification for this very precise figure. I would suggest that at this early stage it is not possible to be so certain: you need to do a few interviews and see what the data look like. If each child is interviewed only once, this will not generate a huge volume of data, so you must make sure that it captures all the information you need – and enough on which to base a 100,000 word thesis.

A bit more information is needed about the interviews with significant others. There is no need to add it into this submission, but you need to be thinking about it next.

Page 18: think very carefully about reliability and validity in qualitative research in the next few months.

You've read all about ethical issues, but you need to apply them more to your study. This will be probably be easier to think about once you have some data and some experience of doing the interviews.

Go forth and collect data and work up your nice protocol some more!

APPENDIX 6: REC Correspondance

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
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North Wales REC (Central & East)

G1/G2 Croesnewydd Hall
Croesnewydd Road
Wrexham Technology Park
Wrexham LL13 7YP

Telephone : 01978 726377

E-mail : tracy.biggs@wales.nhs.uk

Website : www.nres.nhs.uk

20 May 2013

Mrs Amie, S Hodges
PhD Student, Lecturer in Children's Nursing Studies
Cardiff University, Cardiff School of Nursing and Midwifery studies
Room 501 5TH Floor Eastgate House
35 - 43 Newport Road,
Cardiff,
CF24 0AB

Dear Mrs Hodges

Study title: An exploration of the family centred experiences of the sibling in the Cystic Fibrosis trajectory. Siblings, Family and cystic fibrosis
REC reference: 13/WA/0172
Protocol number: sponsor ref 1209-13
IRAS project ID: 121148

Thank you for your application for ethical review, which was received on 17 May 2013. I can confirm that the application is valid and will be reviewed by the Proportionate Review Sub-Committee on 30 May 2013. To enable the Proportionate Review Sub Committee to provide you with a final opinion within 10 working days your application documentation will be sent by email to committee members.

One of the REC members is appointed as the lead reviewer for each application reviewed by the sub-committee. Professor Alex Carson is the name of the lead reviewer for your application.

Please note that the lead reviewer may wish to contact you by phone or email between 27 May and 29 May 2013 to clarify any points that might be raised by members and assist the sub-committee in reaching a decision.

If you will not be available between these dates, you are welcome to nominate another key investigator or a representative of the study sponsor who would be able to respond to the lead reviewer's queries on your behalf. If this is your preferred option, please identify this person to us and ensure we have their contact details.

You are not required to attend a meeting of the sub-committee.

Please do not send any further documentation or revised documentation prior to the review unless requested.



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Documents received

The documents to be reviewed are as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	02	17 May 2013
Investigator CV	Amie Hodges	
Investigator CV	Katie Featherstone	
Investigator CV	Daniel Kelly	
Other: Florence Nightingale Scholarship letter		13 July 2012
Participant Information Sheet: Sibling leaflet/consent	02	17 May 2013
Participant Information Sheet: Parent Information sheet/consent	02	17 May 2013
Participant Information Sheet: Healthcare Professionals Information/consent	02	17 May 2013
Protocol	Dec12	31 December 2012
REC application		20 May 2013
Referees or other scientific critique report		11 January 2013

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

Notification of the sub-committee's decision

We aim to notify the outcome of the sub-committee review to you in writing within 10 working days from the date of receipt of a valid application.

If the sub-committee is unable to give an opinion because the application raises material ethical issues requiring further discussion at a full meeting of a Research Ethics Committee, your application will be referred for review to the next available meeting. We will contact you to explain the arrangements for further review and check they are convenient for you. You will be notified of the final decision within 60 days of the date on which we originally received your application. If the first available meeting date offered to you is not suitable, you may request review by another REC. In this case the 60 day clock would be stopped and restarted from the closing date for applications submitted to that REC.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

For guidance on applying for R&D approval, please contact the NHS R&D office at the lead site in the first instance. Further guidance resources for planning, setting up and conducting research in the NHS are listed at <http://www.rdforum.nhs.uk>. There is no requirement for

separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office for Aneurin Bevan Health Board. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/WA/0172

Please quote this number on all correspondence

Yours sincerely



Mrs Tracy Biggs
Committee Coordinator

E-mail: tracy.biggs@wales.nhs.uk

Copy to: *Helen Falconer, Cardiff University*
Dr Katie Featherstone, Cardiff University
Rosamund Howell, Aneurin Bevan Health Board

APPENDIX 7: Researcher response to REC

Cardiff School of Nursing and Midwifery Studies

Head of School and Dean Professor Sheila Hunt

Ysgol Astudiaethau Nyrsio a Bydwreigiaeth Caerdydd

Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



Cardiff University
Eastgate House
7th Floor
35 – 43 Newport Road
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Tel Ffon: +44 (0)29 20 917800
Fax Ffacs: +44 (0)29 20 917803
Email E-bost
Hodgesa@cf.ac.uk

Prifysgol Caerdydd
7^{ed} Llawr
Ty Eastgate
35 – 43 Heol Casnewydd
Caerdydd CF24 0AB

Professor Alex Carson
North Wales REC (Central & East)
G1/G2 Croesnewydd Hall
Croesnewydd Road
Wrexham Technology Park
Wrexham
LL13 7YP

Dear Professor Carson,

Study title: An exploration of family centred experiences of the sibling in the cystic fibrosis trajectory.

Siblings, Family and cystic fibrosis

Rec reference 13/WA/0172

Protocol number: Sponsor ref 1209-13

IRAS project ID: 121148

Thank you for your response following the Proportionate Review Sub-Committee of the Research Ethics Committee that recently reviewed the above application.

I agree with the panel decision that a full REC review opinion would be useful for this study. I welcome any help, advice or suggestions that the panel are able to provide, to ensure that I am adhering to research governance principles in conducting research which is safe / ethical to provide the utmost protection of the children that I propose to recruit for my research study.

With regard to the panels concerns relating to 'inadequate precautions being in place as the potential for disclosure.' Whilst I understand the issue raised, I would like to reassure the panel that safeguarding the children in my proposed study is my priority, I consider this my duty of care not only as a researcher, but also professionally as a registered children's nurse, in adhering to the Nursing and Midwifery Council Code of Conduct (NMC).

I have attempted to address the issue of recognising how to deal with a situation should a child become upset in

- Section A22 of the IRAS form submitted for review.
- The sibling participant leaflet under the section heading
Might anything else about the research upset me?
- In the parent leaflet
What are the risks to my child?

I have also considered the research ethical guidance in the documents outlined **on page 18/19 in the research protocol.**

I understand that I may not have clearly articulated or signposted my precautionary measures enough and I welcome any suggestions by the panel of changes that may be necessary and I would be keen to implement.

Additionally I have added a list to illustrate the precautionary measures that will be additional information that can be given to children and their families along with the leaflet (precautionary measures version 1. 29/05/13)

As a qualified children's nurse for 24 years, I have had experience in caring for children in disclosure situations and it maybe that it has become so inherent in what I do, that I have not provided the clarity required, so any further advice would be welcome.

I look forward to meeting you on 5th June 2013 at 6 pm at the full REC review meeting.

Yours Sincerely

Amie Hodges

Mrs Amie, S Hodges
PhD Student, Lecturer in Children's Nursing Studies
Cardiff University, Cardiff School of Nursing and Midwifery Studies
Room 501 5th Floor Eastgate House
35-43 Newport Road,
Cardiff
CF24 0AB

Precautionary Measures to safeguard the child participant.

1. A letter will be sent to your child's Gp to inform them of their participation in the 'Listen Hear' project once the study has been explained and consent has been gained from the parent/ guardian/ child
2. A family member will need to be present in the child's home when the sibling is talking to the researcher just in case they child becomes upset
3. Should the child become upset when talking to the interviewer, the interview will be stopped and the child will not be pressured to continue with the project, because the child's needs will be a priority. The child will be made aware that they can withdraw from the research at any time if they so wish, without any explanation.
4. The researcher will be available to discuss any concerns that the child may have and will act in an appropriate manner to ensure the sibling gains any necessary support required. This may include referral to the GP or other healthcare professional if necessary.
5. Any information discussed by the child will be kept confidential and pseudonyms will be used when using material when writing up the thesis. However; should there be any disclosure from the child relating to anything that may cause harm to them or others, the researcher will need to act to ensure the child and families safety. This will include reporting this to the Gp/School Nurse/Other appropriate health care professional. Any untoward incident will also be reported to the researchers supervisor. The child and family will be informed of this verbally and this will be included in the information leaflet to be discussed prior to gaining consent.
6. The contact details of the researcher will be given so that the child and family can contact the researcher for the duration of the research project.
7. The contact details will also be provided to the family of the CF child and family advocate employed by the CF Trust – Kayleigh Olds, who is the named person that is able to support families living in the CF trajectory.
8. At the end of the child's participation in the study, the child will be informed that they can still contact the researcher should they wish to talk about anything, as it is important for the child not to feel abandoned.
9. It is also noted that I have consulted the following other professionals/ service users in putting together this protocol,

because it was important to me to gain multiple subjective opinions in conducting an ethical research project:

- Emma Renold, Professor of Childhood Studies/ Social Sciences Cardiff University
- Kayleigh Old, Child and family Advocate from the CF trust / also a CF patient
- Elizabeth Ward, School Teacher - St Cyrus comprehensive, Penarth, South Wales/ also previously lived with a chronically ill sibling
- A counselling psychologist / Lecturer in Applied Psychology – University of Salford.
- Attended a two-day workshop relating to participatory research approaches with children. Child user representatives were included in the day and provided guidance on formulating leaflets for children and young people.

APPENDIX 8:

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
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Wrexham LL13 7YP

Telephone : 01978 726377
E-mail : tracy.biggs@wales.nhs.uk
Website : www.nres.nhs.uk

06 June 2013

Mrs Amie, S Hodges
PhD Student, Lecturer in Children's Nursing Studies
Cardiff University, Cardiff School of Nursing and Midwifery studies
Room 501 5TH Floor Eastgate House
35 - 43 Newport Road,
Cardiff,
CF24 0AB

Dear Mrs Hodges

Study Title: An exploration of the family centred experiences of the sibling in the Cystic Fibrosis trajectory. Siblings, Family and cystic fibrosis
REC reference: 13/WA/0172
Protocol number: sponsor ref 1209-13
IRAS project ID: 121148

The Research Ethics Committee reviewed the above application at the meeting held on 05 June 2013. Thank you for attending to discuss the application.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	02	17 May 2013
Investigator CV	Amie Hodges	
Investigator CV	Katie Featherstone	
Investigator CV	Daniel Kelly	
Other: Florence Nightingale Scholarship letter		13 July 2012
Participant Information Sheet: Sibling leaflet/consent	02	17 May 2013
Participant Information Sheet: Parent Information sheet/consent	02	17 May 2013
Participant Information Sheet: Healthcare Professionals Information/consent	02	17 May 2013
Protocol	Dec12	31 December 2012
REC application		20 May 2013
Referees or other scientific critique report		11 January 2013



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Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

13/WA/0172	Please quote this number on all correspondence
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Yours sincerely

T.a. Biggs.

P

Professor Alex Carson
Chair

E-mail: tracy.biggs@wales.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

*Copy to: Dr Katie Featherstone, Cardiff University
Rosamund Howell, Aneurin Bevan Health Board*

APPENDIX 9: Favourable Opinion

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Wrexham Technology Park
Wrexham LL13 7YP

Telephone : 01978 726377

E-mail : tracy.biggs@wales.nhs.uk

Website : www.nres.nhs.uk

12 June 2013

Mrs Amie, S Hodges
PhD Student, Lecturer in Children's Nursing Studies
Cardiff University, Cardiff School of Nursing and Midwifery studies
Room 501 5TH Floor Eastgate House
35 - 43 Newport Road,
Cardiff,
CF24 0AB

Dear Mrs Hodges

Study title: An exploration of the family centred experiences of the sibling in the Cystic Fibrosis trajectory. Siblings, Family and cystic fibrosis
REC reference: 13/WA/0172
Protocol number: sponsor ref 1209-13
IRAS project ID: 121148

Thank you for your letter of 07 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.

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 Mrs Tracy Biggs, Tracy.Biggs@wales.nhs.uk.

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.

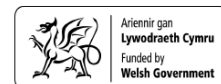
Ethical review of research sites

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).



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The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board



After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WA/0172	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

T.A. Biggs.

AB

Professor Alex Carson
Chair

E-mail: tracy.biggs@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Katie Featherstone, Cardiff University*
Rosamund Howell, Aneurin Bevan Health Board
Helen Falconer, Cardiff University

APPENDIX 10: Sibling Information Sheet / Assent form



The “Listen Hear” Project

A research project with Cardiff University

Participant information sheet

(Sibling)

Who I am?

My name is Amie Hodges and I am a postgraduate student doing research at Cardiff University.

I am asking if you would join in a research project to find the answer to the question:

What are the experiences of siblings within their family when living with a brother or sister with Cystic Fibrosis? (Protocol reference Dec/12)

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, doctor or School Teacher if you want to.



Part One

What's the project about?

I would like to find out more about you and your life:

- What is it like being you? What is it like living in your family?
- What it is like having a brother or a sister with cystic fibrosis?
- What are your needs? Things you like or dislike?
- How would you like things to be for you in your family?
-

What will I be asked to do?

Project Activities:

If you agree, I would like you to do some activities to help with my research project.

Activity 1. Picture/collage

I will be asking you to make a picture collage that will help you to tell me more about you and what it is like living in your family. You can use pictures, drawings, photos, cut outs from magazines or pictures from the computer to make your collage.

I will provide some collage material for you and if there is anything you need to help, you can just let me know.

I will also give you a disposable camera to take some photographs that you may want to include in your collage, if you want to. If you are not sure how to make a collage I can show how to make one.

You will be able to make the collage on your own and in your own time so that you can think about what you want to put in it. We can choose a time for the collage to be finished by. You will have about 4 weeks to make it.



How many picture/collages will I be asked to do?

If you agree, I will be asking you to do 2 collages, but not at the same time. It will be good for you to have a rest between doing each picture collage, so the second one will be at least 4 weeks after doing the first one.

Activity 2. Listening to you

If you agree, after you have completed each picture/collage I would like to come and visit you in your home or somewhere else if you prefer, so that you can tell me about what you have made. I would like to hear about you and your picture. I would like to record some of the things that you talk about and to take a copy of what you make. You can decide on the things that you would like to share with me.

Why am I doing this research?

Children and young people do not always get the chance to talk about their experiences and often not enough is written about their views to help others, like nurses, doctors and researchers to understand what life is like for them.

I am interested in learning more about children and young people who have a brother or sister with Cystic Fibrosis. Finding out more will help me to understand what family life is like for you.

I want to do this project to give children and young people the opportunity to have a say about their experiences, so that I can learn about what is important to you in your family and to help others to learn too!

Can I keep the picture /collage once the study is finished?

Yes, the picture / collage is yours to keep once the study is completed.

Why have I been invited to take part?

You have been invited to take part because you have a brother or sister with

cystic fibrosis and I would like to know more about what family life is like for you. Siblings of children with cystic fibrosis do not always get the opportunity to say what life is like for them.

How many other children will be studied?

This is a new study there will be 12 children in this project. This number has been chosen so that I can spend some time with you to help guide you with the activities and find out more about you.

Who is organising and funding the research?

Cardiff University is the sponsor for the research. The researcher is not being paid for any research activities undertaken.

Did anyone else check the study is OK to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the _____ Research Ethics Committee.

Do I have to take part?

No. It is up to you. I will ask you for your consent and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

Thank you for reading so far – if you are still interested, please go to Part Two:

Part Two

What will happen to me if I take part?

Amie will visit you if you agree.

You will be able to take part in the research activities and you will be asked to make two collages. You will be asked to talk about each of the pictures that you have made with Amie. You will be in the project for no longer than 6 months. A flow chart is provided so that you know what will happen.

Amie will also explain the activities and what will happen.

Will I miss school?

No the activities will take place when you are not in school

Might anything else about the research upset me?

The project is not intended to upset you in any way.

You do not have to talk to Amie about anything that might upset you. If you do become upset when you are talking about the pictures that you have made then you can stop talking and have a rest. You will have a family member at home with you too, so they will be around to support you. Amie has worked with children and young people for a very long time and also be there to talk if you became upset.

Will anyone else know I'm doing this?

I will keep your information in confidence. This means we will only tell those who have a need or right to know. Wherever possible, we will only send out information that has your name and address removed.

Will joining in help me?

I cannot promise the study will help you but it might be useful to you and your family to find out about your experiences. It may also be helpful to other families, brothers, sisters in the future, as well as nurses or doctors working with children in the future.

What happens when the research stops?

When the research stops you can still contact Amie if you need to, but you will not need to do any more pictures for the research.

What if something goes wrong during the project?

It is unlikely that anything will go wrong during the project but we can talk about things if something does happen.

What if I don't want to do the research anymore?

If at any time you don't want to do the research anymore, just tell your parents, or Amie. They will not be cross with you and will not affect any treatment that you or your family are given. You do not have to say why you do not want to do it anymore. Any information gained to that point will remain in the research study, but no further information will be collated.

What if I am not happy with any part of the research / or want to complain?

If you are not happy with anything, please let Amie know. You may want to talk to your parents and they can speak to Amie.

Should you require further information please contact:

Amie Hodges

Cardiff University. Cardiff School of Nursing and Midwifery Studies.

Room 501, Floor 5. Eastgate House

Newport road

Cardiff

Email: hodgesas@cardiff.ac.uk / **Tel:** removed



Sibling Assent Form

Project title The "Listen Hear" Project

(protocol reference Dec/12)

A research project with Cardiff University

To be completed by the Child or young person or with the parent/carer if unable.
Circle all they agree with:

Has somebody else explained this project to you? Yes/No

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand?
Yes/No

Do you understand it's OK to stop taking part at any time? Yes/No

If any answers are 'No' or you don't want to take part, don't sign your name!

If your answers are 'yes' and you do want to take part, you can write your name below

Write your name

Sign

Date

The person who explained this project to you needs to sign too:

Print Name

Sign

Date

Thank you

The researcher will sign the form too

Name

Signature

Date

Thank you for your help.

APPENDIX 11: Parent / Guardian Information Sheet



The “Listen Hear” Project Parent/guardian information sheet

Who I am?

My name is Amie Hodges, I originally trained as a children’s nurse and I am now a postgraduate student doing research at Cardiff University.

I am asking if you would like your child to join in a research project (protocol reference Dec/12) to find the answer to the question:

What are the experiences of siblings within their family when living with a brother or sister with Cystic Fibrosis?

Before you decide if you want your child to participate, it's important to understand why the research is being done and what it will involve for your child. Do talk to others about the study if you wish. Please read part one of this sheet. If you are interested continue to part two of the information sheet.



Part one

What’s the project about?

I am doing a project about children who are living with a brother or sister with cystic fibrosis.

I would like to find out more about the sibling experience and what family life is like for them.

I would like to ask for your help in this project by allowing me to talk to your child about their experiences and what life is like for them when they have a brother or sister with cystic fibrosis. Your child would need to give their permission too.

Why am I doing this research?

I am doing this project because children and young people do not always get the chance to talk about their experiences. Also often not enough is written about their views to help others, like nurses, doctors and researchers to understand their world.

Why has my child been invited to participate?

Your child has been invited to take part because they have a brother or sister with cystic fibrosis and I would like to know more about what family life is like for your child. Siblings of children with cystic fibrosis do not always get the opportunity to say what life is like for them and gaining information may help in the gaining of new knowledge to help children, their families and healthcare professionals.

What do I plan to do?

I have planned to ask your child to be involved by making a picture/ collage that will help them to tell me about what life is like for them.

Once the collage is finished I would like to ask your child to talk to me about the picture that they have made. I will be asking them to make two pictures on separate occasions, so that will mean talking to your child on twice. I will talk to your child for no longer than one hour and if your child needs a break from talking, then that is fine.

I would like to tape record our conversation to help me to remember what we have talked about and to help me write my project. Any information collected, recorded and reported on will be kept confidential. I will have two supervisors and an examiner checking my work and so names and places will be changed to make sure confidentiality is maintained.

When I have completed the project I would like to share what I have learnt from my work with healthcare professionals and researchers. In doing so, again confidentiality will be maintained.

How many other children will be studied?

This is a new study there will be 10 children in this project. This number has been chosen so that I can spend some time with your child to help guide them with the activities and find out more about their experiences and views.

Who is organising and funding the research?

Cardiff University is the sponsor for the research. The researcher is not being paid for any research activities undertaken.

Has this study been approved?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the _____ Research Ethics Committee.

Does my child have to take part?

No. It is up to you and your child. I will ask you and your child for your consent/assent and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

What if I would like my child to participate, but they do not want to?

If your child does not want to participate, they will not be included in the study.

Part Two

Where will the project take place?

Your child will be able to make their picture collage at home within an agreed time frame. I will then talk to your child at home, unless there is somewhere specific that they would prefer to talk – for example at the University or in their school.

Will my child need to take time off school?

No, your child will not miss any school, research activities will take place outside of school hours and at mutually negotiated times.

Are there any costs involved in the project?

There will be no costs incurred to you or your child when partaking in this project. I can provide materials required for the picture collage. Your child can choose what they want to use and if there is anything additional that they specifically need then I can provide it. I will also provide your child with a disposable camera if they would like one. I will pay for the photographs to be developed and your child can choose if they want any to be included in the study.

What are the risks to my child?

Your child will only be asked to talk about what they are comfortable with. If they become upset at anytime during the study activity or interview then we can stop. I am experienced in caring for children and young people so if your child did become upset for any reason I would be able to talk to your child. Also it is important that a family member is present in the home when the research is taking place. If your child became unduly upset for any reason, I can also inform your GP if they needed further support. The activities are largely guided by your child as a participant, so any risk foreseen is minimal.

What are the benefits for my child?

Your child will get the opportunity to discuss his/her experiences within the family when living with a brother or sister with cystic fibrosis. It may benefit your child if they share their views about their experience and needs. It will also help inform other families and health care professionals working with children and young people for the future.

Will my child taking part be kept confidential?

Information gained in the study will be kept confidential and where information is written/published about in the research findings, pseudonyms will be used. All data collected will be stored securely in a locked cupboard and only the researcher will have access.

The following authorised persons; the researchers the supervisors, examiners, sponsors, regulatory authorities & R&D audit will also have access to information for monitoring the quality of the research.

In accordance with Cardiff University guidance on conducting research with children and young people , data collected will be kept for 15 years and then disposed of securely.

What if I want to make a complaint?

If you have any concerns about the study or if your child raises any concerns please contact Amie. Alternatively if the issue cannot be resolved please contact Dr Katie Featherstone. Floor 4 Eastgate House, Newport Road. Cardiff.

How can I contact you if I have any questions and would like my child to take part?

If you would like your child to take part you can

Contact:

Amie Hodges

Email: hodgesas@cardiff.ac.uk

Telephone: removed

Post: Room 501, East gate House
Newport Road, Cardiff,

APPENDIX 12: Web recruitment

Web recruitment request information:



Information that will be placed on a Parent web Forum (cystic fibrosis forum)

My name is Amie Hodges and I am a research student in the school of nursing at Cardiff University

I am doing a project about children age 8 to 12 who are living with a brother or sister with cystic fibrosis.

I would like to find out more about the sibling experience and what family life is like for them.

I would like to ask for your help in this project by allowing me to talk to your child about their experiences and what life is like for them when they have a brother or sister with cystic fibrosis. They will be asked to participate in a couple of activities that will include making a picture/collage. Your child would need to give their permission too.

I am doing this project because siblings of children with cystic fibrosis do not always get the opportunity to say what life is like for them and gaining information may help in the gaining of new knowledge to help children, their families and healthcare professionals.

If you are interested in finding out more about this project please contact:

Amie Hodges on email hodgesas@cardiff.ac.uk

Or telephone. Removed

APPENDIX 13 Parent / guardian consent form



**Consent Form
Parent / Guardian**






I would like my child (print name)

.....

**To take part in the 'Listen Hear' project.
(Protocol ref Dec/12)**

Please initial each box below if you agree

- I agree to my child taking part in the planned project activities that have been outlined
- I understand the project and confirm the study has been explained to me.
- I understand that there will be no costs incurred to me, when taking part in the project.
- I agree to the conversation between my child and Amie to be recorded.
- I understand that my child can have a break or stop talking to Amie at any time during the study.
- I understand that my child can withdraw from the project at any time.
- I understand that if my child chooses to withdraw it will not affect them or any family member if they required help in the future.

- I understand that confidentiality will be maintained throughout the project. 
- I understand that Amie will share what she has learnt with others to help inform them about the sibling experience and that confidentiality will continue to be maintained. 
- I understand that Amie will work ethically and professionally at all times when conducting the research.  
- I have a copy of Amie's contact details 
- I understand that if I wish to make a complaint I can do so by contacting Dr Katie Featherstone. Cardiff University, Floor 4 Eastgate House. Newport Road. Cardiff.



Print Name
Signature
Date

Researchers Name
Signature
Date

APPENDIX 14: Sibling Activity Project Plan

Project Activity	What will happen?	Duration
Meeting the sibling and the family	Amie will talk about the study and there will be time for questions and answers. We can discuss the need for consent. Discuss the collage and the requirement of any materials. Amie will give you her contact number.	Approximately 20 minutes with your parent/guardian Approximately 20 minutes with the you Total time - no longer than 1 hour.
Getting to know you session	Before we start any activities, Amie would like to spend some time with you so that you can get to know each other a bit more. You can choose what you want to do at this visit.	Approximately 1 hour
Picture / collage 1 'Me and My Family'	I would like you to make a picture collage linking to the theme that we will discuss called ' me and my family'	You will have up to 4 weeks to do this in your own time. You can organize how long you will need with Amie.
Narrative Interview 1 'Me and My Family'	Amie will visit you and you can tell her about your picture collage. This is the time for you to say whatever you want about your picture. Amie may ask you some questions about your picture and ask you to talk about you and your family. When we talk about your picture I will record our	This will take about 45 minutes and no longer than one hour.

	conversation if you agree. This will help me to remember what you say.	
Time Out Break	This is time for you to have a rest after your hard work in answering questions and doing your collage. You can contact Amie during this time if you need to.	Break for at least 4 weeks and no longer than 12 weeks. Arrange with Amie how much time you need for a break.
Picture Collage 2 'future selves'	I would like you to make a picture collage linking to the theme that we will discuss called 'future selves' this relates to how you see things for yourself in the future, how you would like things to be for you.	You will have up to 4 weeks to do this in your own time. You can organize how long you will need with Amie.
Narrative Interview 2 'future selves'	Amie will visit you and you can tell her about your picture collage. This is the time for you to say whatever you want about your picture. Amie may ask you some questions about your picture and ask you to talk about you and your family. When we talk about your picture I will record our conversation if you agree. This will help me to remember what you say.	This will take about 45 minutes and no longer than one hour.
This is the end of the project	You can still contact Amie if you need to.	Thank you for helping me with these activities

**APPENDIX 15: Florence Nightingale Foundation Research Scholarship
Award 2013/2014**



The Florence Nightingale Foundation

34 Grosvenor Gardens, First Floor Front, London SW1W 0DH
Tel: 020 7730 3030
Fax: 020 7730 6262
Email: admin@florence-nightingale-foundation.org.uk
www.florence-nightingale-foundation.org.uk

5 July 2013

Amie Hodges

Dear Amie

**THE FLORENCE NIGHTINGALE FOUNDATION RESEARCH SCHOLARSHIPS: THE
GENERAL NURSING COUNCIL FOR ENGLAND AND WALES TRUST RESEARCH
SCHOLARSHIP 2013-2014**

The General Council for England and Wales Trust

The Selection Panel were delighted to have the opportunity to meet you at your recent Skype interview.

Through the generosity of The General Council for England and Wales Trust we are pleased to offer you an award of £1,950.00 to assist you in undertaking the 2nd year of your PhD, on What are the experiences of siblings within their family in the chronic illness trajectory? This money will be paid either to the University where you are undertaking your course or directly to you, as required. In either case, we would need to have sight of an invoice or receipt as appropriate.

Would you thank Dr Sam Koroma, on behalf of the GNC at the address below.

Dr Sam Koroma
The General Nursing Council for England and Wales Trust
83 Victoria Road
London N9 9SU

The terms and conditions of acceptance of this scholarship are:

- The Foundation require a short six month review report by the end of March 2014 to update us on your progress.

- I attach some notes for guidance on report writing plus front covers for your report. A full report on your research (two hard copies and one on CD or stick) should reach The Foundation on completion of your studies covered by this award. Your report should include an acknowledgement of The General Nursing Council for England and Wales Trust and The Florence Nightingale Foundation, and be presented in a clear plastic cover.
- You should also send a copy of the report to your sponsor at the end of your scholarship.
- Your final report should be submitted within 3 months of completion of your year of study i.e. no later than 29 November 2014.
- Your sponsor may also ask you to give a formal presentation on the outcome of your studies at a future meeting; we will liaise with you on this nearer the time.
- If asked, you should be willing to present your work at a Foundation conference.
- We also ask you publish something as a result of your scholarship. By accepting this award you agree to the Foundation sharing intellectual property rights generated as a result of this scholarship.
- By accepting this award we also hope that you will be happy to become an Alumni of The Foundation to help support future scholars within your area of expertise. Unless you inform us otherwise we will keep your electronic personal data on file and contact you with relevant information and opportunities to collaborate with The Foundation.
- If your home address or employment details change before you have submitted your report, you are required to keep the Foundation up-to-date with your contact details at all times.
- In the event that you do not undertake the study and produce an acceptable report for which this award is being made, you will return to The Foundation the money you have received, in order that it may be used to fund another Scholar.

If you accept the award in accordance with the conditions set out above in this letter, ***please sign one copy and return it to me as soon as possible, but by 23/7/13 at the latest*** keeping the second copy for future reference.

If you require any further information, please do not hesitate to contact this office.

With best wishes and congratulations on this award.

Yours sincerely



Professor Elizabeth Robb
Chief Executive

I accept this award on the conditions set out above and undertake to refund the money if circumstances outlined above apply.

.....
.....

Name

Date

APPENDIX 16: Florence Nightingale Foundation Research Scholarship
Award 2014/2015



The Florence Nightingale Foundation

34 Grosvenor Gardens, First Floor Front, London SW1W 0DH

Tel: 020 7730 3030

Fax: 020 7730 6262

Email: admin@florence-nightingale-foundation.org.uk

www.florence-nightingale-foundation.org.uk

14 July 2014

Mrs Amie Hodges

Dear Amie

THE FLORENCE NIGHTINGALE FOUNDATION RESEARCH SCHOLARSHIPS 2014-2015: THE BAND TRUST RESEARCH SCHOLARSHIP 2014-2015

The Selection Panel were delighted to have the opportunity to talk to you again at your recent skype interview.

Through the generosity of The Band Trust we are pleased to offer you an award of £1,995.00 to assist you in undertaking the 2nd year of your PhD October 2014 to September 2015, on What are the experiences of siblings within their family in the chronic illness trajectory? This money will be paid either to the University where you are undertaking your course or directly to you, as required. In either case, we would need to have sight of an invoice or receipt as appropriate.

Would you please write and thank The Hon Mrs Nicholas Wallop, Chairman at The Band Trust.

Her address is: The Hon Mrs Nicholas Wallop
The Band Trust
4 Lexham Mews
London W8 6JW

The terms and conditions of acceptance of this scholarship are:

- The Foundation require a short six month review report by the end of April 2015 to update us on your progress. This needs to be a brief update of no more than 500

words which can be sent to the administrator at admin@florence-nightingale-foundation.org.uk as an attachment in a word document.

- I attach some notes for guidance on report writing plus a front cover for your report. A full report on your research (two hard copies and one on CD or stick) should reach The Foundation on completion of your studies covered by this award. Your report should include an acknowledgement of your sponsor and The Florence Nightingale Foundation, and be presented in a clear plastic cover.
- You should also send a copy of the Abstract of your report to your sponsor at the end of your scholarship.
- Your final report should be submitted within 3 months of completion of your year of study but no later than 18 December 2015.
- Your sponsor may also ask you to give a formal presentation on the outcome of your studies at a future meeting; we will liaise with you on this nearer the time.
- If asked, you should be willing to present your work at a Foundation conference.
- We also ask you publish something as a result of your scholarship. By accepting this award you agree to the Foundation sharing intellectual property rights generated as a result of this scholarship.
- By accepting this award we also hope that you will be happy to become an Alumni of
the Foundation to help support future scholars within your area of expertise. Unless you inform us otherwise we will keep your electronic personal data on file and contact you with relevant information and opportunities to collaborate with The Foundation.
- If your home address or employment details change before you have submitted your report, you are required to keep the Foundation up-to-date with your contact details at all times.
- If you have a significant period of sickness or any event that may impact on the completion and/or submission of your final report, you are required to inform the
Foundation as soon as possible to negotiate a new submission date if required.

- In the event that you do not undertake the study and produce an acceptable report for which this award is being made, you will return to The Foundation the money you have received, in order that it may be used to fund another Scholar.

If you accept the award in accordance with the conditions set out above in this letter, **please sign one copy and return it to me as soon as possible, but by 29/7/14 at the latest** keeping the second copy for future reference.

If you require any further information, please do not hesitate to contact this office.

With best wishes and congratulations on this award.

Yours sincerely



Professor Elizabeth Robb
Chief Executive

I accept this award on the conditions set out above and undertake to refund the money if circumstances outlined above apply.

.....
.....

Name

Date

APPENDIX 17: Florence Nightingale Report feedback 2013



The Florence Nightingale Foundation

34 Grosvenor Gardens, First Floor Front, London SW1W 0DH

Tel: 020 7730 3030

Fax: 020 7730 6262

Email: admin@florence-nightingale-foundation.org.uk

www.florence-nightingale-foundation.org.uk

6 December 2013

Amie Hodges

Dear Amie

Thank you for your final report of your first year of your Phd. I am delighted that you have achieved so much in preparing yourself by undertaking the further research methods and research literature. The experiences of children with siblings with cystic fibrosis is such an interesting area of practice and will I am sure lead to care improvements and better working with and support of families. Excellent to hear that you have gained Ethics approval having refined your research question. We look forward to further progress after your data collection in your 2nd year report.

As you know, part of your Scholarship is now to go on and publish your work to ensure the widest spread. There are two Journals that the Foundation is in contact with whose Editors have offered to help Scholars if required. These are the *British Journal of Nursing*, and the *International Practice Development Journal*:

<http://www.britishjournalofnursing.com/> & <http://fons.org/library/author-guidelines.aspx>.

Of course you can choose any other relevant journal.

Please keep us informed of your progress on these as we and your sponsor would wish to receive a copy of the publications and to be acknowledged in any article as well as sharing the intellectual property rights generated as a result of this scholarship.

Unless you inform us otherwise we will consider you to be an Alumnus of The Foundation and keep your electronic personal data on file, contacting you with relevant information and opportunities to collaborate with The Foundation.

Please do publicise our Scholarships to your colleagues, as we have more funds available for next year. Finally, I hope you are planning to join us at our Conference on 27th & 28th February 2014 (information is attached). Have a lovely Christmas and New Year.

Kind regards

Elizabeth Robb.

Elizabeth Robb
Chief Executive

APPENDIX 18: Florence Nightingale Foundation report feedback 2014



The Florence Nightingale Foundation

34 Grosvenor Gardens, First Floor Front, London SW1W 0DH

Tel: 020 7730 3030

Fax: 020 7730 6262

Email: admin@florence-nightingale-foundation.org.uk

www.florence-nightingale-foundation.org.uk

22 December 2014

Mrs Amie Hodges

Dear Amie

Thank you so much for your final Scholars report of the 2nd year of your PhD. I enjoyed reading it and was very pleased to see that you have now recruited 9 out of the 10 participants for your research and data collection for half of the cohort. We really look forward to seeing further progress on this really interesting and important study over the next year. It is great that you have presented posters and papers.

As you know, part of your Scholarship is now to go on and publish your work. There are two Journals that the Foundation is in contact with whose Editors have offered to help Scholars who are not experienced in publishing. These include the *British Journal of Nursing*, and the *International Practice Development Journal*:

<http://www.britishjournalofnursing.com/> & <http://fons.org/library/author-guidelines.aspx>.

It would be great to have a copy of any publications please as a result of this year's work.

Please keep us informed of your progress on this as we and your sponsor would wish to receive a copy of the publication and to be acknowledged in any article as well as sharing the intellectual property rights generated as a result of this scholarship.

As a completed scholar we would like to retain your name and contact details on file so that we may contact you with relevant information and opportunities to collaborate with the Foundation. If you wish us not to do this, please let us know.

We also very much hope that you will consider joining our recently launched Alumni Association (flyer attached) which is free to join for the first year www.fnfalumni.org

Please do publicise our Scholarships to your colleagues, as we have more funds available for next year. Finally, I hope you are planning to join us at our Conference on 12th and 13th March 2015 (information is attached).

Kind regards

Elizabeth Robb
Chief Executive

APPENDIX 19 Brocher Foundation Research Scholar Award

Brocher Foundation visiting stay 2014

Brocher Foundation, Anyck Gérard <a.gerard@brocher.ch>

Amie Hodges; Fri 19/04/2013 14:34

Inbox

SELECTION – BROCHER FOUNDATION CALL FOR VISITING RESEARCHERS - 2014

Dear Amie Hodges,

We are pleased to inform you that your proposal “Siblings, families and cystic fibrosis” has been selected for implementation during the 2014 Brocher Foundation programme and wish to congratulate you.

Due to the high level of the proposals and considering our maximum capacity to host researchers during next year, the Brocher Foundation faced the difficult task to evaluate and finally to select the projects to support.

After an extensive evaluation and consultation period, the Scientific Committee of the Foundation decided to shortlist a number of projects that fitted best the criteria.

The projects have been analysed namely under the following aspects:

1. Scientific background of each candidate
2. Scientific relevance and innovative field aspects of the project
3. Congruence with the Brocher Foundation’s scientific agenda and programme
4. Time period of the stay and congruence with the presence of other Junior and Senior researchers in order to create research synergies and facilitate scientific cooperation

The Brocher Foundation will provide you with an office and a bedroom at the Brocher Foundation, for a stay from 02.10.2014 to 29.10.2014. This includes breakfast and one dinner per day.

As the aim of the Brocher residencies is also to gather together researchers from various cultural and scientific backgrounds, we stress that researchers are expected to attend the daily dinners.

The Foundation will make a special effort to find suitable housing and offices. We warmly thank those who managed to change their travel dates to help us to find a solution.

We would finally kindly ask you to sign the enclosed “Statute for the 2014 visiting researchers” and send it back to us by latest August 31st, 2013 at

Fondation Brocher, 471 Rte d’Hermance, CP 21, 1248 Hermance, Switzerland

We stay at your entire disposal for any further information you may need,

Yours sincerely

Cécile Caldwell Vulliétty

General Secretary

Brocher Foundation

Rte d’Hermance 471

CP 21

CH - 1248 Hermance

Switzerland

Telephone: +41 22 751 93 93

Fax: +41 22 751 93 91

www.brocher.ch

APPENDIX 20: Cardiff University Student Alumni Award



Sheila King
on behalf of
Bursaries and Scholarships
Amie Hodges; Katie Featherstone; Wed 01/05/2013 11:17
Dear Amie ,

Following your recent application to the Cardiff Student Alumni Awards, I am pleased to be able to inform you that you have been awarded a grant of £ 450.00 towards the cost of your conference and visit.

I would remind you that a condition of this award is that you provide a short report (approximately 300 words with photograph if possible). This report should indicate the benefit you gained from this experience. The report must be completed and returned no later than the one month after the conference. Is the conference this August or next August?

Please provide details to receipts to show the conference fee as soon as possible so we can arrange a payment to you. We will require copies of the receipts after you have paid.

Our best wishes for the successful completion of your trip. I look forward to reading your report.

Sheila King

Bursaries & Scholarships
Financial Support Team , Student Support Centre,
50 Park Place, CF10 3AT
Tel 029 2087 9128 / 9320 bursariesandscholarships@cf.ac.uk,

APPENDIX 21: Notification of presentation abstract acceptance Institute for patient and family centered care.



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

6917 Arlington Road, Suite 309 • Bethesda, MD 20814 • Phone: 301-652-0281 • Fax: 301-652-0186 • www.ipfcc.org

Date: June 2014

Re: Amie Hodges Florence Nightingale Foundation Research Scholar/ PhD student Cardiff University to participate in International Conference

Contact: **Amie Hodges** / hodgesas@cardiff.ac.uk

Racquel Codling, Director, Special Projects and Educational Programs
Institute for Patient- and Family-Centered Care — 301-652-0281

Amie Hodges a Florence Nightingale Foundation Research Scholar and PhD student of the School of Healthcare Science, Cardiff University has been selected to present at The 6th International Conference on Patient- and Family-Centered Care: Partnerships for Safety and Quality, August 6-8, 2014, in Vancouver, British Columbia. The three-day conference is hosted by the Institute for Patient- and Family-Centered Care, headquartered in Bethesda, Maryland, with leadership support from Providence Health Care in Vancouver, British Columbia and support from our program partner, the Canadian Foundation for Healthcare Improvement, based in Ottawa, Ontario.

Amie will present

' The listen hear' project: Using visual elicitation and narrative inquiry to explore the family centered care experiences of siblings in the cystic fibrosis trajectory.

Highlighting best practices in patient- and family-centered care.

It is indeed an honor to have been selected to be a presenter from the nearly 400 abstracts submitted.

The 6th International Conference on Patient- and Family-Centered Care offers more than 100 plenary and concurrent sessions and over 60 posters highlighting patient- and family-centered

strategies and exemplary programs dedicated to collaboration among health care professionals, patients, and families. Conference presenters will share the value of partnering with patients and families to address current challenges in health care including the risk of medical error, improving transitions in care, redesigning the primary care system, increasing numbers of people living with chronic conditions, expanding use of technology, the need for new facilities, and the pressure to control costs.

This conference will offer examples of excellence relevant to a variety of settings including: hospitals and health systems; primary care, medical home, and ambulatory specialty care; community-based programs; mental health and public health agencies, rehabilitation and long-term care; schools of medicine, nursing, allied health, and other health professions; and, patient- and family-led organizations.

Participants, from across the United States, Canada, and other countries, will learn best practices for planning, implementing, and evaluating patient- and family-centered initiatives and learn how to guide their organization to create sustainable partnerships with patients and families. These powerful partnerships are essential to redesigning health care and improving quality, safety, and the experience of care.

For more information about the Conference, visit www.ipfcc.org or call 301-652-0281.

#

The Institute for Patient- and Family-Centered Care (IPFCC), a non-profit organization founded in 1992, provides essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support. For more information, visit

APPENDIX 22 Telephone Interview with Grace (Parent of CF siblings)

Field work – Telephone interview with Grace Trent (Pseudonym are used)

People

The Trent family

Mother of a 2 ½ year old with CF and a 4½ year old non CF sibling

Dad

Names changed for confidentiality purposes

Mother – Grace

Dad - Joe

Child with CF – Skye

Sibling without CF - Bluebell (Belle for short)

Place

At the researchers home in the evening 7pm scheduled telephone interview sat in the lounge.

At Grace's home in England she was talking on the phone whilst Dad was bathing the children and getting them ready for bed.

Context

I was contacted by Grace via email she had seen my posting on the CF forum and wanted to help inform my study. She explained in her email that she was married and had 2 siblings Skye and Belle one with CF and one without and that even though the sibling without CF was not in my age bracket for my study that she would be willing to talk to me to discuss her experience. In order to gain background information and further insight I made the decision to respond to Grace and following further emails we arranged for a mutually convenient telephone interview. (Emails to be copied over).

Grace informed me that Jo worked away a lot and came home from work late so would arrange to speak when dad was home.

“In Skye's shadow”

Grace talked about her experiences of having 2 children with one having CF and the other one not. She explained how initially Belle had had a relatively 'normal' life until she was 2½ years old when Skye came along. That was when everything changed, “things change when you have a child anyway but for Belle it was a bigger change because Skye had CF”

“At first we tried to hide it from Belle” Grace had not wanted to expose Belle to the CF and what the treatment entailed.

“ We sent Belle to her Gran as we thought that was best at first, but she (Belle) became really upset because she thought she had been sent away”.

Grace discussed how at that time she had not really thought about how it would affect Belle because the attention needed to be focused on Skye, her diagnosis and treatment.

“The last person you think about emotionally is the sibling” Grace expressed that it would have been nice if she had not had to expose Belle to Skye’s CF.”

Grace gave an example of today when she was busy with Skye and Belle wanted her attention and Grace was pre occupied I would never say to Belle I am busy with Skye, but Belle knows and she said “I know you are not listening to me”

Grace discussed how when people are visiting the house (healthcare professionals) they are coming to see Skye for her CF, they are not coming to see Belle, the attention is on Skye. It is the same at the hospital everyone is interested in Skye and Belle is on the sideline. It was not until we went to GOSHH as we moved her from a different hospital and they had a Pyschologist and one of the things they asked me was how is the sibling? I had never been asked before, that was when it made me think about the impact on Belle.

Grace discussed how having a sibling with CF had an impact on Belle “She became anxious and did not want to leave the house” “She went through a stage of wetting herself “and we have had to have the help of a psychologist to help find a suitable school for Belle. They are trying to find a suitable school for Belle that will be able to have an understanding of her needs in living in the context of CF.

Grace mentioned that At nursery when she drops Belle off she will comment whether Skye is not well and Belle may not be herself, but she does not think they realise the impact on Belle and it probably just goes in one ear and out of the other.

“She is OCD (obsessive compulsive) and very particular and worried about germs, she still is now.”

Within the family she will say

“Don’t cough around Skye” “Don’t sneeze around Skye”

It was important within the family to not expose Skye to any germs that may exacerbate her CF symptoms and getting PA (Pseudomonas Aerogenosa) is something that they want to avoid.

Grace discussed how “Belle is in Skye’s shadow, she is always on the sideline, she is like the outsider, always there at the side watching what is going on” as a baby things were normal for Belle but since having Skye and the having the CF in the family, things have been different, but we have had to adapt and this has become our normal.

She talked about when Skye is not well and they will bring her downstairs when Belle has gone to bed. Belle will ask “why is Skye downstairs and we will say well it is because she is a baby and Belle will say no she is not she is a big girl now because she is 2”

“How do you explain that, because in the day I will say to Skye you are a big girl not a baby anymore.”

“Jo and I try not to talk about CF and what is happening in relation to Skye’s treatment because it was taking over our lives and was affecting the family as a whole. We do not want it to become our focus. When Jo comes home we talk about normal everyday things as opposed to the focus being on CF treatments. It really does impact on the siblings and on the couples relationship.”

“Someone bought the girls a little medical set but I threw it away in the end because they were re enacting the treatments and giving the IV’S.”

Grace talked about when Skye was diagnosed they became friends with 8 families who had a newly diagnosed CF child and she discussed how the divorce rate is high and that couples of children with CF often do not stay together

“Out of the 8 families we got to know only 2 are still together”

Grace and Jo have made a conscious decision to change their own behaviour and how they speak about the child’s day so that it does not consume the family day or impact on them and the children.

Mealtimes

“You want to hide CF but you can’t hide it from the sibling”

Grace provided an example in terms of mealtimes and eating

She discussed how Skye requires 1,000 extra calories per day because of the CF and she also needs Creon added to her food. She requires extra fat in her diet.

(creon are enzymes to help with digestion of the food. Children with CF do need the extra calories because the disease impacts on their ability to digest food/ nutrients and they would fail to thrive, hence they also require added vitamins).

Grace discussed how they need to encourage Skye to eat and will give her desserts and high calories drinks and then Belle with question that and she will say ‘ why can’t I have a dessert?’

There is a dilemma because they do not want Belle to have the extra calories as this would make her fat. Whereas they need Skye to have the extra calories, because she has problems maintaining her weight. So every mealtime is a time when you cannot hide CF.

Grace discussed how Skye does have a weight problem and it is difficult for her to maintain weight “we give her extra encouragement and attention to get her to eat. Belle has noticed this so she started leaving her food so that she could get the extra attention at mealtimes.” “I mean how do you explain to a 21/2 year old that you are different?”

“Skye is beginning to notice things at mealtimes now and she will say I don’t want creon, give it to Belle.” Or with other treatments she will say “why does Belle not have to do this.”

“And then Belle will become a little helper, siblings are little helpers, if we are out and in a café Belle will be giving Skye her creon capsules off a spoon and I can see people looking and they are probably thinking why is that child giving medicine to the other child?” “They don’t understand but it is her normal”

“Sometimes we have been out and Belle will want a drink and I have not got the Creon so what do I do? Do I let Skye have a drink if Belle is having one and then I have not got the creon and then she may end up with the tummy ache. You have to try and balance it out sometimes”.

Grace discussed how the Psychologist had been helpful and had said that it was okay to let Belle help if she wants to. The Psychologist normalised things and said that often a sibling may want to help to change a babies nappy or help with bathing only in Skye’s situation she needs help in relation to the CF treatments. Grace informed me that there is a constant transition and adaptation as each child develops.

She mentioned how Belle has now started going swimming at a grotty local leisure pool and Skye has said ‘why can’t I go swimming?’ and now I have to say to Belle ‘Don’t tell Skye you are going swimming’. Skye cannot go to the baths because she would pick up germs. So there is this secrecy.

Mum talked about looking for school for Belle and needing to find a smaller school because when she is with a lot of people in a big school she will retreat into the background and lose her identity but in a smaller group she is better.

Grace commented on the lack of support available for siblings and how she felt more was needed to raise awareness of the impact on CF families. She also commented on CF being a hidden illness and she compared it to how people perceive / react to children with a cancer diagnosis. She commented not to say it was less of a disease but how people do not realise it is life limiting and with cancer there can be a cure but for CF there is not. She commented on the facilities at the hospital for families with cancer children but that there is not the same perception for

the needs of CF families. She talked about CF being a hidden disease that people did not understand and were not familiar with. She perceived that there was not enough awareness in advocating for the disease. She commented that she personally did not find the CFTrust as helpful as she would like it to be. A lot of parents tend to formulate their own closed groups so that the CF trust and the hospitals staff consultants cannot access it. They feel they can then speak more freely. "Not many families use the forum, they are mainly in closed groups."

There is minimal information for siblings or support from the CF forum was her perception.

Finding out that Skye had CF was a dark spiral for Grace and she had suffered with post natal depression.

Grace discussed her awareness of different genotypes and how she knew that even though the life expectancy has increased, if you have the most severe genotype then the people that she knew were only living into their 20's and would be on the list for lung transplants.

"No one else can understand what it is like to live with CF in the family unless you are experiencing it yourself in the immediate family". Grace states " even our own wider family do not realise the enormity of it all"

"More support is needed for siblings, I will place information on the closed groups for you because I know others would be interested to help".