

**An Interpretative Phenomenological Analysis of the
Transition from Child to Adult Services for Young
People with Cystic Fibrosis and their Families in
Wales**

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ABSTRACT

The process of transition of care provision from paediatric to adult services can be a stressful time for service users and their families in that it can add to the burden of patients and their families living with a life-limiting illness. This thesis will explore the lived experiences of young people and parents in making this transition between children's and adult cystic fibrosis (CF) services in Wales. It uses Interpretive Phenomenological Analysis (IPA) which has its focus on the 'double hermeneutic', a two stage interpretation process whereby the participant tries to make sense of their world and the researcher tries to make sense of the participant, making sense of their world (Smith 2008).

Through the use of semi-structured in-depth interviews, the experiences of participants were sought and analysed using IPA's layered approach to the data. These layers; the descriptive, the conceptual and the linguistic served to reveal the life world of young people and parents who found themselves disenfranchised from the comfort and perceived safety of children's services.

The data suggest that the meanings of transition were different for the young people who, with one exception, largely saw it as a positive experience. The parent group however reported feelings of loss and exclusion and were often critical of the care offered by the adult service. This apparent conflict was examined and the findings of the study suggest that the philosophical differences in care giving were the site of this tension. The model of family centred care espoused in the children's service fosters inclusion and cooperation with parents actively involved in care-giving, whilst the patient-centred approach of adult services has its focus on self-efficacy and co-production. The result, for parents, is more of a 'cliff-edge' transition while the young people seem to see it more as a 'rite of passage' into adulthood.

This thesis, which adopted the Bridges Model of Transition (2009) as its conceptual framework, offers new insights into a process which is becoming more commonplace as, what were once terminal, childhood conditions now progress to adult care services. It also offers recommendations for service providers (particularly in child care) to assist in fostering a process of disengagement and re-engagement which will minimise disruption and stress for all those involved.

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Chapter One

Introduction to the Thesis

1.0: Introduction

This thesis seeks to explore the experiences of young people with cystic fibrosis (CF) and parents who have made the transition from children's services to the adult CF healthcare services located in a large healthcare provider in Wales. As parents also have a considerable involvement in their child's care within children's services, the thesis also seeks to examine the parental experience of the transition process. By utilising an Interpretive Phenomenological Analysis approach, it is hoped that the voices of those making this transition or who are witness to it, will be heard and that the meanings of the participants ascribing to those experiences are captured. In doing so, the study will hopefully add to the current understanding of the transition processes involved, as well as informing future policy development.

1.1: *Background to the Study*

My interest in adolescent health and, in particular transition, has been long standing. Between the late 1980's and the early 1990's, I worked on an adolescent unit in Melbourne, Australia, where approximately 50% of our patient group had CF. At that time, the average life expectancy of an individual with CF was somewhere between the early to mid-twenties. At a variable point in time, young people would transition from the adolescent unit (housed within the children's hospital) to the adult CF unit, which was in a different location. I have always enjoyed working with young people, their energy, enthusiasm and sense of fun can be inspiring, but they can also be quite cynical. For a time, our CF patients all wore tee shirts emblazoned with '*Life's a Bitch - and Then You Die*' across the front as a sort of 'badge of office'. Cynical? Yes but, from their perspective, probably true. However, it was a conversation I had with a group of young people one night that really sparked my interest. They were discussing a friend with CF who had recently undergone transition to adult services, when someone said 'so she'll be gone soon then'. I was surprised when the comment received a number of nods and murmurs of agreement, but on probing further into this, it became evident that the adolescents with CF thought that when they made the transition to adult services, it was because they were ready to die. In fact, one of them articulated that 'they send you over there so you are not on the kids hospital statistics when you die'. This level of cynicism clearly matched the

tee shirts but was this really what they thought? Apparently so, and despite a considerable level of discussion and reassurance that this was not the case, none of them would be swayed: transition was a not so subtle hint that their time was limited and they were going to die soon.

Throughout my career I have continued to take an interest in transition although the opportunity to undertake research in this area did not present itself for some time. On returning to Wales I took up my current position, the remit of which was to increase the level of adolescent health content within the undergraduate nursing curriculum and to examine the feasibility of developing an adolescent health module / programme. Having achieved this, my position was made substantive and after a time, I had the opportunity to undertake further study. Based on past experience and more up to date local research, I decided that my research would focus on adolescents with cystic fibrosis and their transition from child to adult healthcare services within Wales. As a consequence, my thesis places a considerable emphasis on adolescence and adolescent development. However, due to circumstances which will become evident as the thesis progresses, the experiences of parents were also sought.

1.2: The Research Study

This research aims to build on recommendations from the Department of Health (DoH) document *Transition: Getting it Right for Young People with Long Term Conditions from Children's to Adult Services* (2006) as well as guidelines from both the Royal College of Paediatrics and Child Health (RCPCH) (2007) (*Bridging the Gaps: Health Care for Adolescents*) and the Royal College of Nursing (RCN) *Adolescent Transition Care: Guidance for Nursing Staff* (2013) in relation to the provision of transitional care services. All of which will be discussed in more detail under section 1.3.

1.3: Policy Context

Due to the increasing longevity of individuals with chronic health conditions, young people with CF will eventually need to move from child to adult healthcare services to continue their care. Consequently the need to develop new, and improve on existing transition services within the UK, has been an important issue for some time. As a consequence, a range of documents such as; *Transition: Getting it Right for Young People with Long Term Conditions from Children's to Adult Services* (DoH 2006), *Bridging the Gaps: Health Care for*

Adolescents (RCPCH 2007) and Adolescent Transition Care: Guidance for Nursing Staff (RCN 2012) have been published identifying transition as an area that needs to be given priority consideration.

The DoH document Transition: Getting it Right for Young People with Long Term Conditions from Children's to Adult Services (DoH 2006) is an evidence based guide to good practice that recognises the need for an effective planned, well-managed handover between child and adult services. Using evidence from the USA, Canada, Australia and the UK, this document recognises the need to provide effective transition services due to the increased longevity of young people with chronic health conditions (DoH 2006). The document further outlines the need for young people to be supported through the transition process and encourages them to take responsibility for their own health management. Recognition was also made of the need for an appropriate level of service delivery as well as utilising staff who are able to provide appropriate levels of high quality care and support to young people (DoH 2006).

From a medical perspective and prior to the DoH (2006) document, the Royal College of Paediatrics and Child Health (RCPCH) produced the report, Bridging the Gaps: Health Care for Adolescents (RCPCH 2007). This report started by providing an overview of adolescent healthcare within the 21st century and then went on to outline more specific areas of adolescent health, including the general lack of specialised adolescent units to provide hospital care for young people. In relation to transition, the need for improving services was identified, particularly for young people with conditions that had previously only been considered as limited to childhood, and the need for "hand-over clinics" (RCPCH 2007 p38) was advocated. The RCPCH (2007) recognised the considerable differences in management styles between the family centred care (FCC) approach of children's services and the self-care approach in adult services, which had the potential to add to the difficulties adolescents experienced during transition. The suggestion was made that joint hand over clinics facilitated by child and adult services staff may help to alleviate this (RCPCH 2007).

The Royal College of Nursing (RCN) has also published a document specifically pertaining to transition; Adolescent Transition Care: Guidance for Nursing Staff (2013). Similarly, to the RCPCH document, in the document published by the RCN (2013), an overview of the need for transition services was identified in

addition to recognising the inconsistencies in management within this area. Adolescent Transition Care: Guidance for Nursing Staff (RCN 2013) provides a guide for best practice to enable nurses to assist in facilitating a smoother transition to adult services. Within this document, potential barriers and facilitators of the transition process are identified. The RCN (2013) also recognises the need to provide on-going education for nurses caring for adolescents and advocates multidisciplinary training for all staff working with young people.

All of these documents identify the need for transitional services and highlight the importance of providing safe and effective transitional services for young people with a range of chronic conditions. In addition to this, all the documents recognise that transition should be well planned and coordinated and stress the importance of involving young people and parents in the transition planning process. Therefore, the documents identified here relate to this current research, as they either identify the need for improving adolescent healthcare provision overall, highlight the need for effective transition programmes or offer guidance on facilitating a smooth transition to adult services.

1.4 :Research Question

The primary research question for this study was:

What are the lived experiences of young people and parents following transition from child to adult CF services in Wales?

1.5: Research Outcomes

The primary research outcome for this study was to:

Successfully articulate the lived experiences and the sense making of young people and parents following the transition from children's to adult CF services in Wales.

1.6 : Definition of Key Terms

There are three main topics of discussion within this thesis; adolescence, CF and transition and each of these will be discussed in more detail in the following sections. However, it is important to provide an operational definition for what is understood by each of the terms used within this thesis. An explanation of these terms will be provided within the following sections.

1.6.1: Adolescence

In contemporary society there are a number of terms used to describe adolescence including; youth, teenager, adolescent and, the more recent terms of young people or young adults (Rice and Dolgin 2008). In 1993, the World Health Organisation (WHO) suggested that the following definitions should be used; *adolescents* for individuals aged between 10 -19 years of age, *youth* for those aged between 15-24 years and *young people* when they are between the ages of 10-24 years (WHO, 1993). More recently, WHO (2014) suggested that the age limit of 'young people' could even be expanded to the early to mid-thirties. Therefore, throughout this dissertation the terms adolescent/s and young people will be used interchangeably to represent individuals between the ages of 18 to 35 years, as this is reflective of the age group of the younger participants within this study.

1.6.2: Cystic Fibrosis (CF)

CF is an inherited progressive life limiting condition that predominantly affects the respiratory and gastrointestinal systems. However, a range of other bodily systems are also affected and the impact this condition has on the individual can be considerable (Al-Yateem 2012) and varies with individuals. Although longevity of individuals with CF has improved over time, this is a life limiting condition and children, adolescents and young adults still die prematurely. Furthermore, the physical (and psychological) impact that this condition has on the individual can be considerable and young adults still die and for those who do not die prematurely, their health and well-being can be severely compromised.

1.6.3: Transition

The term transition has been used for a number of years to describe the process of moving patients' care from children's services to adult services within a healthcare setting. Within this thesis, when transition is referred to it will be based on the standard definition for transition that is used in the majority of publications pertaining to transition and was developed in 1993 on behalf of the Society for Adolescent Medicine (SAM) as:

the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health-care systems...[t]he optimum goal of transition is to provide health care that is

uninterrupted, coordinated, developmentally appropriate,
psychosocially sound and comprehensive.
(Blum et al. 1993 p570)

The following sections will discuss all of these topics in greater detail.

1.7: Introduction to Adolescence

The need to provide appropriate levels of health care to individual patients is a key priority within the health care setting. Targets are constantly being set in an attempt to improve care standards (Bevan 2006) and the importance of undertaking research which will translate into providing evidence based care, is recognised (Grol and Grimshaw 2003). However, I would argue that one area where improvements to care standards are not always evident is within adolescent health. Although the majority of adolescents are healthy individuals who have limited contact with health care providers (Hagel et al. 2013), there are times when health care provision is necessary. It is vitally important therefore that appropriate care strategies and facilities are in place. In countries such as the United States of America (USA) and Australia considerable research is undertaken in all areas pertaining to young people and within health care 'adolescence' is viewed as a speciality in its own right. Therefore, a considerable amount of research undertaken in these countries aims to improve care standards. Although, as I have argued, the United Kingdom (UK) lags behind the USA and Australia in the development of adolescence as a distinct speciality, the development of adolescent services within UK health care settings is slowly increasing.

Approximately 11.7 million young people aged 10-24 years live within the UK (Hagel et al. 2015). Coinciding with this, improvements in health care provision within neonatology and paediatric specialities have seen increasing numbers of young people with a chronic illness surviving to adolescence and adulthood (Doug et al. 2011, Westwood et al. 2014). There are difficulties in accurately assessing the number of adolescents who have a chronic illness. This is due, in part, to an individual perception of what actually constitutes a chronic illness and the reliance of self-reporting when collecting this data (Michaud et al. 2004). However, it is recognised that health problems within the adolescent population appear to be increasing (Viner and Booy 2005), with approximately 20 – 30% of children living in developed countries having been diagnosed with a chronic illness (Yeo and Sawyer 2005) and an estimated 15% of these, within the UK

(Hagel et al. 2013). Therefore, it is logical to suggest that as medical and health care advancements continue to move forward, the numbers of adolescents surviving with a chronic illness will increase, necessitating the eventual transfer or transition of care from child to adult healthcare services.

This has implications for policy development and the provision of services for adolescents in general (Coleman and Schofield 2005). It also sends a clear message that individuals within the healthcare profession need to become more aware of, and develop strategies to meet, adolescent healthcare needs (Bill and Hodges, 2007). Despite this, within the UK, adolescent research in general is limited in comparison to the USA and Australia and there is a lack of current, empirical research literature related to transition. Additionally, specific research related to CF and transition is limited (Doug et al. 2011, Fegran et al. 2013) and to date, no research relating to the transition between child and adult services for young people with CF and parents has been undertaken in Wales.

Therefore, the experiences of young people with CF and parents following the transition from child to adult services, in Wales, have been sought. Information gained from this will assist greatly in the development of a clear transition pathway or the enhancement of the current level of transition service provided to young people within Wales.

To enable a full understanding of the needs of young people with CF, it is essential to develop an understanding of adolescence itself. Adolescent development is complex with physical, cognitive and psychosocial development inter-twined, but not necessarily synchronised (Rice and Dolgin 2008). However, I would argue, that knowledge of the adolescent developmental process is vital for anyone wishing to work with young people, and develop, deliver or improve healthcare services, as this would ensure the provision of age appropriate care. Therefore, in the following section, operational definitions will be provided in relation to the main components of this thesis; adolescence, CF and transition. This will include an outline of the development of adolescence, which includes a brief historical background. An overview of adolescent physical, cognitive and psychosocial development will be provided to demonstrate its complexity and to highlight the way in which this has the potential to impact on the provision of care. As CF forms a major focus of this thesis, the diagnosis, aetiology, management

and the way in which CF impacts on the adolescent will also be discussed. Finally, a definition of transition and the need for this service will be offered.

1.7.1: Adolescence: An Overview

The range of terms used in contemporary society to describe adolescence has been identified under section 1.4.1. WHO, first presented these definitions in 1993, however, the definitions are confusing as they overlap considerably and do little to rectify the problem of clearly defining adolescence. More recently, the overlap and confusion of terms were recognised by WHO (2014) in their publication *Health for the World's Adolescents: A Second Chance in the Second Decade*. In this document, WHO (2014) identified, that the ages assigned to their own definitions may also vary between different countries and that the age limit of 'young people' could even be expanded to the early to mid-thirties. It is not clear why WHO decided that young adulthood ceased in the mid-thirties, as some authors, (Geiger and Castellino 2011) suggest that the term 'young adults' can be used for individuals up to the age of 39 years. Equally one could argue that it is an arbitrary cut off point, again without any clear foundations.

However, it is not surprising that a confusion of terms in relation to defined age groups has arisen as adolescent development itself is complex and does not always follow an age-defined template. Therefore, throughout this thesis the terms adolescent/s and young person / people will be used interchangeably to represent individuals between the ages of 18 to 35 years, as this is reflective of the age group of the younger participants within this study. This is also reflective of the titles of documents prepared by government and professional bodies that will be referred to within this work.

The word adolescent is derived from the Latin *adolescere*, meaning "to grow to maturity" (Rice and Dolgin 2008 p2). It is important to keep this translation in mind as in relation to the topic of this thesis, adolescence itself is a transitional period, which occurs between childhood and adulthood and involves a considerable level of physical, cognitive and psychosocial change (Santrock 2001). Within developed countries, the word 'adolescence' has become an accepted term used to describe young people of varying ages, genders and backgrounds who are not children but have not yet reached adulthood. In contrast, this is not so in all countries, as the worldwide adolescent population is diverse and in many cultures young people, particularly boys, need to move

through some form of 'rites of passage' to become adults (van Gennep 1960, Rice and Dolgin 2008). Therefore, the concept of adolescence could be viewed as a construct that relates predominantly to developed countries. Furthermore, within developed countries, the period of adolescence appears to be lengthening and becoming increasingly complex (WHO 2014). This is an interesting phenomenon, particularly as it can be suggested that adolescence as a distinct age period itself is a relatively new concept. In recognition of this, the term 'child' or 'children' will be used within this section of the thesis, as this is reflective of the historical context.

1.7.2: Adolescence: An Historical Perspective

The intention of this section is to provide a background to the concept of adolescence and has relevance to this current study as it places adolescence in context. It also demonstrates that although there is some historical basis to adolescence as a construct it has its basis in more recent times. Therefore, a brief outline of adolescence throughout history will be provided and following this, consideration will be given to changes that occurred in the late 1800s within North America, as it is generally accepted that this is where the concept of adolescence was developed (Viner 2008).

Prior to the development of adolescence as a construct, individuals were classed either as children or adults, although the term 'youth' was also commonly used (Leyser 2003). It was not uncommon for children to work from the age of five or six years and they were expected to undertake 'adult' work by 13 years of age (Paterson 2008). As a consequence, for the majority of children, "childhood was a brief and unimportant phase of life" (Duckworth 2002 p5).

The increased mechanisation of farming in the 19th century caused Britain to witness a considerable shift of people from country areas into the cities in search of work. In general, conditions were dire and 'wayward children' were, becoming a considerable problem for the authorities. In large cities such as London, Manchester and Liverpool, 'street kids' were common with more than 100,000 "beggar boys sleeping rough in Covent Garden" (Duckworth 2002 p10). By the mid-1880s, London alone held an estimated 350,000 children either in workhouses or correctional facilities, many of whom were awaiting transportation to Australia (Rees 2001). Individuals were viewed as either children or adults and by 1821 the legal 'age of consent' was established at 12 years of age for girls

and 14 years of age for boys (Stainton Rogers 2005) although it is unclear why a differentiation between the sexes was made. As an individual 'grew and developed' they simply moved from being a child to being an adult, with no recognition of any developmental shift between the two periods. Although many influential Victorians, including the authors JM Barrie and Charles Dickens, attempted to address the problems of the poor and destitute using a philanthropic approach, there was little improvement in the lives of children, particularly those from lower socio-economic backgrounds and conditions did not begin to change until the advent of the Children Act of 1908 (Stainton Rogers 2005).

1.7.3: The North American Perspective

If the industrial revolution changed the way of life in Britain, by the mid to late 1800s it was also changing the North American way of life. However, America took a distinctly different approach to both the mechanisation of the country and the way in which children were viewed. In particular, whilst Britain continued to view children and adults as two groups albeit with blurred boundaries, in America the concept of 'adolescence' developed from changes to the perceived structure of the American way of life. Children living within British and American rural families initially had similar lifestyles, working on the land with their parents in distinct male and female gender roles (Fergusson Clement 1997). However, in contrast to children from British rural areas, many homesteads were isolated and the socialisation of farm children was predominantly limited to their siblings. The mechanisation of American farming increased the middle class structure where more emphasis was placed on education and improvement (Fergusson Clement 1997). Nevertheless, America was not a country without problems and, as with their British contemporaries, many children worked from as early as five years of age (Fergusson Clement 1997).

As the level of industrialisation increased, the movement of people from rural to more urban areas became greater. Children, who had previously remained closeted within the confines of their homestead, were now able to seek the friendship of individuals from a wider geographical area. This change in culture caused considerable concern for older generations. Consequently, various parent groups were established who advocated strongly that the practice of widening friendships and outside influence should be curtailed (Demos and Demos 1969). It is clear therefore, that the adult American population were concerned that they were losing touch with, and 'control of', their children.

1.7.4: The Development of Adolescence

In contrast to the philanthropic approach favoured in Britain, in North America, the focus of the majority of early American literature was on the growing 'problems' associated with the American family way of life. This approach focused on suppressing the desire of the young to socialise outside home in an attempt to stop what was viewed as an erosion of parental authority (Demos and Demos 1969).

Interestingly however, what emerged from this debate was the fact that there was now a distinction being made between younger children and older children, with the later becoming known as 'youth' (Demos and Demos 1969). This new subculture of 'youth' became a contemporary focus of attention for authors particularly regarding 'problems' with authority. Consequently, in relation to this perceived lack of respect for authority, since the early 1900s adolescents have been consistently portrayed in a negative manner, which is far from being a constructive approach (Irwin et al. 2002) and still persists in contemporary society (Casey et al. 2010).

1.7.5: The Influence of Grenville Stanley Hall

Regardless of the predominantly negative themes and content, it was on the basis of this emerging body of North American literature that the concept of adolescence was developed. Without question, the most influential person in the development of adolescence was the psychologist G Stanley Hall, (1844-1924). In 1904, Hall's book entitled *Adolescence*, the first of two volumes, was released (Hall 1904) with *Adolescence, its Psychology*, being released four years later (Hall 1908). At the time, Hall's work was widely credited as being ground breaking. However, the importance of Hall's work has been diminished over the decades as new ideas and concepts have been developed (Arnett 2006). One major contemporary criticism of Hall's theories is that he firmly grounded his thinking in Lamarckism.

Lamarckism is essentially the belief that inherited traits, characteristics or memories can be passed on from parent to child (Kronfeldner 2007) and in the past, this concept was given substantial consideration by many evolutionists and anthropologists. However, more recently, Lamarckism as a theory has been largely refuted since the discovery of genetics (Arnett 2006), although it is still a published topic (Kronfeldner 2007). To a certain extent, Richard Dawkins (2009,

30th Anniversary Edition) in his book *The Selfish Gene* bases his discussion surrounding *memes* on Lamarckian principles, suggesting that ideas and concepts are passed on from person to person, until the idea “propagates itself” (p192). Dawkins (2009) identifies music and fashion as examples of this, and it is easy to see where this sits within adolescence and the development of a specific adolescent culture. From this viewpoint it is possible to imagine how Lamarckism *may* have an indirect influence on cultural evolution (Kronfeldner 2007). This could have been what Hall recognised and why he based many of his theories on the Lamarckian Concept. However, it is important to move past Hall’s more radical views and recognise his actual contribution to the development of adolescence.

Hall identified adolescents as being between the ages of 14-24 years and he provided commentary on a variety of issues pertaining to adolescents (Arnett 2006). The majority of Hall’s work was insightful and he identified issues that are as relevant to adolescents today as they were to adolescents in 1904. The tendency towards depression and fluctuating moods, thrill seeking behaviour, the importance of peers and the way in which adolescents can be influenced by the media and their peers were all described in some detail by Hall (Arnett 2006). However, Hall was the person who first described adolescence as a period of ‘storm and stress’ (Casey et al. 2010) it could also be suggested that in some ways Hall has also done adolescents a disservice. Although the concept of ‘storm and stress’ only occupied a small portion of Hall’s work, it has been this issue that has had a considerable influence on the majority of subsequent adolescent theories and related publications and this continues into contemporary literature.

1.7.6: Hall and Contemporary Adolescence

Since the publication of Hall’s work *Adolescence* in 1904, there have been numerous theories on the concept of adolescence, in particular work by Sigmund Freud (1853-1939) and Anna Freud (1895-1982). Sigmund Freud was a protégé of Hall and it was Hall who sponsored Freud’s move to America (Arnett 2006). Consequently, Freud was heavily influenced by Hall’s work and in turn Anna Freud was heavily influenced by her father’s work. Therefore, she perpetuated her father’s (and Hall’s) theories and continued to focus on the theme of ‘*sturm und drang*’ (storm and stress). However, this continued interest in storm and stress has not been helpful as for some time it overshadowed the considerable impact that the hormonal changes occurring during adolescence have on mood

fluctuations (Rice and Dolgin 2008) the continued focus on storm and stress in adolescence is outdated.

Although some aspects of Hall's work such as the influence of the peer group and the media continue to be relevant, Hall viewed adolescents through the perspective of the particular cultural and historical period of his own time (Arnett 2006) and as such, some of his ideas are no longer relevant in contemporary adolescence. However, it has to be noted that Hall had a considerable influence on subsequent adolescent theorists (Casey et al. 2010) and that prior to Hall, there were undeniably only two distinct age groups, children and adults. Hall's theories enabled the recognition and development of a third category, adolescence. It could be argued therefore that without Hall's influence, the concept of adolescence would not have been developed, and as a consequence, it was important to include reference to his work in this thesis.

There were however other individuals who influenced the development of adolescence and in the early stages of this thesis two particular adolescent theorists were given consideration in relation to the development of a theoretical framework.

1.7.7: Havighurst's Theories of Adolescence

Robert Havighurst (1900-1990) started his career as a physicist, but changed direction in the 1920s when he moved into experimental education. Havighurst developed what he called the 'tasks of adolescence', which were based on adolescent progress and progression from a developmental and educational perspective (Havighurst 1956). However, even with some modification to the original concepts being undertaken in the 1970s, this theory is still a somewhat dated perspective. The three main constructs of this theory are:-

- Physical maturation
- Cultural pressure
- Individual aspirations or values

Indeed his theories were still somewhat in vogue when I undertook my adolescent qualification overseas in the 1990s. However, when these constructs are viewed in more detail, the fact that they are increasingly out of step with

contemporary adolescence becomes more evident. Havighurst's main constructs are divided into eight specific tasks of adolescence:-

- Accepting one's physique and using the body effectively
- Achieving new and more mature relations with age mates of both sexes
- Achieving a masculine or feminine social sex role
- Achieving emotional independence from parents and other adults
- Preparing for an economic career
- Preparing for marriage and family life
- Desiring and achieving socially responsible behaviour
- Acquiring a set of values and an ethical system as a guide to behaviour

(Havighurst 1956)

Havighurst's tasks are in keeping with the ideas of the time and are not unique to his own thinking, as some of these tasks can also be closely aligned to Erikson's tasks of 'achieving identity' (Erikson 1950). According to Havighurst, unless adolescents undertake these subconscious tasks, they will not be able to function fully as adults. However, in contemporary adolescence, issues such as preparing for marriage are not always important, and as young people become more comfortable with their own sexuality, conforming to stereotypical masculine and feminine gender roles is no longer necessary. Additionally, due to periods of economic recession, company restructuring and closures of a range of businesses within the UK in recent years, not all young people have had the opportunity to develop their career as they may have wanted to. Therefore, using Havighurst's 'Tasks' as a guideline to achieving adult status is no longer appropriate as it does not relate to the views and lifestyle of contemporary adolescents. Leaving aside the outdated beliefs and values of these tasks, it is clear that the tasks of adolescence do not sit well with adolescents who have CF. Due to their health, many young people with CF, will have difficulty in 'accepting their physique' due to their poor nutritional status and the potential adverse effect this has on their physical development. As many young people still need assistance with their healthcare management, gaining full emotional independence is not always achieved. Additionally, for some (but not all) adolescents with CF, a career, marriage and a family are not always possible.

Based on Havighurst's theories, adolescents with CF who were unable to accomplish these tasks would not be classified as 'adults'. However, having worked extensively with young people who have CF, I would suggest the opposite. Many young people with CF (and a range of other chronic illnesses), are often more cognitively mature than their peers.

1.7.8: van Gennep: Rites of Passage

Another popular adolescent theory relates to 'rites of passage' although this is again somewhat dated. The concept of rites of passage was first identified by Arnold van Gennep (1873-1957) an ethnographer and folklorist, who was of Dutch and German descent, although he lived in France for most of his life. Consequently his book *Les Rites de Passage*, (*The Rites of Passage*) was originally published in France in 1908. van Gennep's theories sat well within anthropological studies, as he was particularly interested in religious beliefs and ceremonies, which he believed should be witnessed in their entirety and within societal context (van Gennep 1960). Although many of these ceremonies did have an anthropological basis in religion or 'magic', van Gennep firmly based his theories on positivism. Recognising the uniqueness of the various ceremonies he witnessed, van Gennep identified some commonalities between them and grouped these into three main phases, which taken as a whole, became the rites of passage.

- Separation,
- Transition
- Incorporation.

Van Gennep's use of the word transition, in this context relates to moving between two states of mind or moving from one stage to another, often with some form of purification rite between the two (van Gennep 1960). As this study is investigating the move or transition from child to adult services for young people with CF, it is easy to suggest that this theory would fit well with the current study. Indeed, the possibility of using this as a theoretical framework for this study was considered when I was given the opportunity to discuss this at some length during one of my doctoral reviews early on in my candidature. However, transition is only one part of van Gennep's work, and it would be difficult to make 'the whole', as opposed to 'the part', fit within this thesis. Over time, van Gennep

applied his theories to a range of situations, including ceremonies that were associated with natural events, such as cyclical seasonal changes. He was also interested in the ritual and ceremony that surrounded everyday life events, such as birth and childhood, betrothal, marriage, and funeral rites. Consequently, there are really only a few sections of the theory that relate solely to adolescence. One area that van Gennep did specifically focus his interest on, was 'initiation rites'. It is this feature of his work that has been incorporated into some aspects of adolescent developmental theory, and has evolved into the 'rites of passage'. However, again, this was only a part of van Gennep's work. In relation to initiation rites, a range of ceremonies, from initiation into various (sometimes secret) societies to the ordination of priests (van Gennep 1960) were included and studied.

With regard to adolescence and rites of passage, van Gennep did pay particular attention to puberty, sexuality, and the way in which this was recognised or celebrated as a transition to adulthood, for both males and females. However, this again is discussed from an anthropological perspective, and covers a variety of tribal customs, from a range of settings across the globe, which were being practiced at the time. Although transition from child to adult services *could* be viewed as a 'rite of passage', this would only be utilising a small and focused part of van Gennep's overall theory, and to a certain extent, taking it out of context. Additionally, as with Havighurst's work, van Gennep's work is also out of step with contemporary adolescence with the added handicap of structuring his thoughts and theories around an anthropological perspective. Therefore, the discussion surrounding adolescence has been included in this study to place adolescence within context and was not intended to provide an in-depth cultural review of adolescence as a whole. Neither is this study researching adolescents from a cultural perspective, which is the main focus of van Gennep's work.

1.7.9: Adolescent Development

Adolescence itself can be viewed as a transition period between childhood and adulthood. Adolescent development is therefore complex and encompasses physical, physiological, hormonal, cognitive, psychological and psychosocial change (Rice and Dolgin 2008). Although the majority of change is subtle, there are times when physical change can be rapid and visible. Girls usually start their growing period before boys, but the duration for both sexes is the same (Rice and Dolgin 2008). It is important to note that physical and cognitive development do

not run in synchronisation. Consequently, it is possible for physically underdeveloped adolescents to have a greater level of cognitive awareness than their more physically developed peers and vice versa, which is particularly relevant where a chronic illness is present. Therefore, the developmental changes of adolescence are fundamental to the approach that needs to be taken with adolescents on a personal, educational or health care level (Bill and Knight 2007).

Some adolescents have difficulty in coming to terms with their changing bodies and this has implication for body image as well as their overall level of well-being. In general, the process of adolescent development is divided into three phases; early, middle and late (Rice and Dolgin 2008) although Santrock (2001) suggests a two phase (early and late) approach. However, the clearest method of approaching adolescent development is from the three phase approach and this is outlined in Table One.

Table 1: Stages of Adolescent Development

Area of Change	Early (11-14 yrs)	Middle (14-17 yrs)	Late (17-20/5 yrs)
Physical Growth	Rapid Growth. Secondary sex characteristics appear.	Decelerating growth in girls. Reach 95% adult height.	Physically mature. Reproductive growth almost complete.
Cognition	Limited abstract thought. Comparison of 'normal' with same sex peers	Abstract thinking developed. Still idealistic in thoughts. Concerned with political and social issues	Abstract thought established. Can perceive & act on long term issues. Established functional and intellectual identity
Identity	Preoccupied with body changes. Conforms to group 'norms'. Attractiveness measured by acceptance / rejection of peers.	Body image modified. Self-centred, Idealistic. Variable ability to perceive failure & implications of behaviour	Gender role / body image almost secured. Mature sexual identity. Self-esteem – stable. Definition & articulation of social roles.
Parental Relationships	Defining boundaries for independence. Self-conflict – need to remain dependent on parents. Desire for	Conflict-control / independence. Difficulties in parent / adolescent relationship. Significant struggle for emancipation. Disengagement with	Emotional / physical separation from family complete. Independent with less conflict. Emancipation almost secured

Peer Relationships	more freedom. Conflicts with parental control	final detachment from parents	
	Start of peer identification Mainly same sex friendships Dating and intimacy limited	Stronger peer identification. Standards of behaviour set by peer group. Acceptance by peers very important / fearful of rejection.	Increase in individual relationships. Development of intimate relationships. Relationships more reciprocal. Gender role defined.

Bill and Knight (2007 p6)*

Reproduced from Bill S and Knight Y 'Adolescence': In: F Valentine and L Lowes (Eds.) (2007) *Care of Children with Chronic Illness*. Oxford: Blackwell Publishing.

* Originally Modified from Hockenberry M, Wilson D, Winklestein M L and Klein N E (2003) *Wong's Nursing Care of Infants and Children*. (7th edn.) St. Louis: Mosby. (p.804)

1.8: Cystic Fibrosis

Cystic Fibrosis (CF) was first recognised as an individual condition in 1938 (Davis 2006) and is one of the most common life limiting, inherited conditions (Hockenberry et al. 2003). The management of CF is multifaceted and places high demands on the individual and their families. Due to improved technology and care, children with chronic conditions and disabilities are now living longer and CF, once considered to be a childhood condition, is a good example of this. In the 1930s the life expectancy of children with CF was limited and few survived past their first birthday (Davis 2006), this increased to 5 years of age by the 1950s and by the 1970s the mean age of survival was 16 years of age (West and Mogayzel 2016). However, for children with CF, life expectancy has steadily increased over a 50 year period, to between 30 to 40 years of age (Cowland 2003) and within the next decade this could increase to 50 years of age (Simmons 2013). Approximately 45% of the CF population are over 18 years of age and as such, are legally defined as adults (Flume 2009).

1.8.1: Prevalence and Aetiology

The incidence of CF appears to be reducing over time with estimations of between 1 in 2500 (James et al. 2002), 1 in 3300 (Hockenberry et al. 2003) or 1 in 4000 (Winter 2006) live births. There is no clear reason provided for this but it is possible that numbers are reducing due to the availability of and improved techniques related to antenatal screening. CF is relatively uncommon, although it does occur, in individuals of South American, African American (1:15,000) live

births) and Asian (1:31,000 live births) descent (James et al. 2002, Jackson and Pencharz 2003). Due to the rarity of the condition, carrier status is not readily known for other ethnicities (Winter 2006). In the UK, 1:25 people are carriers of the CF gene and approximately five babies are born each week with this condition. Where both parents have the CF gene for each pregnancy there is a 1:4 chance of having a baby born with CF (James et al. 2002, Jackson and Pencharz 2003). In 2014, there were 10,356 individuals with CF in the UK, 374 of whom live in Wales (UK Cystic Fibrosis Registry 2016).

CF is a multi-system disorder caused by a gene mutation on the long arm of chromosome 7. This in turn decreases the stability of the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) which codes the protein essential for chloride transport (Lukacs et al. 1993, Jackson and Pencharz 2003). Effective chloride transportation is blocked and the exocrine glands, which normally produce thin, slippery secretions such as saliva, tears, sweat, mucus and digestive juices, instead produce thick, sticky, viscous secretions. These secretions form mucus plugs, which in turn blocks a range of ducts within the body, including those within the digestive and respiratory systems. The mucus plugs inhibit the passage of enzymes to the digestive system causing problems with absorption, and sitting within the respiratory system they cause repeated lung infections. CF predominantly affects the digestive and respiratory systems, although other areas of the body are also affected (Lukacs et al. 1993, Jackson and Pencharz 2003).

Since the location of the CF gene was identified in 1989, over 2000 different mutations of the gene have been localised (Veit et al. 2016) and as only just over 80 deletions (or alleles) are tested for, it is not uncommon for some of the rarer deletions to be missed (Davis 2006). Many of the rarer deletions have less severe symptoms as some chloride channel activity may still be present, which limits the overall effects on the digestive and respiratory systems (Davis 2006). However, the most common deletion, which affects approximately 70% of the CF population, is the $\Delta F508$. This is a deletion of phenylalanine at the position of the 508th amino acid (Veit et al. 2016). This deletion leads to the most commonly known overwhelming array of effects that CF has on the respiratory system, intestinal tract, biliary tract, liver, reproductive system and pancreas (Jackson and Pencharz 2003). In CF, the severity of symptoms varies between individuals and changes as the condition progresses (Hockenberry et al. 2003). However,

potential complications of CF include; nasal polyps, asthma, haemoptysis, pneumothorax, cirrhosis of the liver, pancreatitis, peptic ulcer, intestinal obstruction, rectal prolapse, gall bladder disease, renal calculi, renal failure, arthritis, osteoporosis and hypertension (UK Cystic Fibrosis Registry 2016). In many cases, damage to the pancreas leads to CF related diabetes (CFRD) which requires management with insulin (Moran et al. 2009). Approximately, 27% of the CF population have been diagnosed with CFRD (UK Cystic Fibrosis Registry 2016).

Eventually, individuals with CF colonise a variety of pathogens in the lungs, most commonly *Pseudomonas Aeruginosa* and *Burkholderia Cepacia*. Over time, symptoms become more pronounced and the individuals overall condition will deteriorate. Predominantly, however, the main cause of morbidity and mortality are repeated lung infections. Colonisation with *Burkholderia Cepacia* for example, is known to be associated with a rapid reduction in lung capacity and an increased level of mortality (Baumann et al. 2003) and it is for this reason that patients hospitalised with CF are managed in isolation (Badlan 2006). Other complications such as pneumothorax and haemoptysis can also lead to progressive lung damage, atelectasis, emphysema and respiratory failure (Davis 2006, Winter 2006, Geller and Rubin 2009).

1.8.2: Diagnosis

CF can be diagnosed through the Newborn Screening Programme and a positive sweat test (Jackson and Pencharz 2003). Some infants receive a provisional diagnosis of CF if they develop a meconium ileus shortly after birth, as this is commonly associated with CF (Lai et al. 2000). For families with a history of CF, pre-natal testing can be offered (Davis 2006) and in some cases amniocentesis and chorionic villus sampling can be used to ascertain the genotype of the foetus (Davis 2006).

Within the UK, the majority (over 55%) of individuals with CF are diagnosed within the first year following birth (UK Cystic Fibrosis Registry 2016). However, many children / young people have a more complicated path to diagnosis and as neonatal screening did not occur in the UK until 2007, diagnosis of CF in young people and adults still occurs (UK Cystic Fibrosis Registry 2016). Additionally, the argument that some individuals remain completely undiagnosed has been presented for some time (Warwick 1980). Although the paper by Warwick is

dated, there is no evidence to suggest that this situation has changed, particularly where the individual has mild symptoms or only experiences single organ symptoms (Gilljam and Björck 2004). Investigations for infertility have also led to some late diagnoses, as males with CF generally have an absence of the vas deferens (UK Cystic Fibrosis Registry 2016) whilst other individuals have been diagnosed as late as 60 years of age (Gilljam and Björck 2004). Commonly, these individuals would have limited symptoms (Hodson 2000). It is also possible that very rare mutations can be overlooked altogether (Davis 2006).

1.8.3: Current Management

The main aim of management is to ensure that the individual remains as healthy as possible for as long as possible. This will enable optimum growth and development in children, reduce the number of chest infections and subsequent hospitalisations and help to facilitate a relatively normal lifestyle (Doull 2001). The management of CF is complex, time consuming and consists of three main areas, dietary management / nutrition, respiratory management and medication management. It is suggested that the optimum way to manage CF is from specialist centres by multi-disciplinary teams (Flume et al. 2001, Doull and Evans 2012), although this does not always occur. In Wales, there are two CF centres one for children / young people and one for adults (UK Cystic Fibrosis Registry 2016). Although some 'shared care' may take place in regional hospitals under the supervision of the specialist CF teams, the majority of CF management for all patients in Wales is undertaken at one of the CF centres, both of which are situated in Cardiff.

Dietary management (Davis 2006) includes a high fat, high calorie diet, with additional dietary supplements and vitamins (Gardner 2007, Hughebaert et al. 2007). Synthetic enzymes are taken before the majority of food types (Davis 2006). Supplemental feeding, often via a gastrostomy tube is common, particularly in infants and children, although this can still occur in adolescence (King et al. 2008).

The aim of respiratory management is to clear lung secretions, reduce lung infections and minimise the risks of colonisation of the lungs with one of the more virulent pathogens (Badlan 2006). This is achieved by using a combination of physiotherapy and exercise. To enable adolescents to undertake their own physiotherapy, various devices such as the Acapella™ Flutter™ and the PEP™

mask have been developed. All of these devices assist in clearing the airways by exerting a pressure through a series of single flow valves (Newbold et al. 2005) thereby increasing lung capacity and function (West et al. 2010).

Medication regimes in CF can be complex and include oral, inhaled, subcutaneous and intravenous medication. For many children and young people repeated peripheral intravenous (IV) access necessitates the insertion of a Portacath®, which is an implanted venous access device, to administer medication (Warwick and Elston 2011). However, as the majority of individuals with CF die from associated lung disease (Geller and Rubin 2009), many new innovations have focused on improved antibiotic therapy (Tonelli and Aitken 2001). The development of 'mucolytic' (DNase® or Pulmozyme®) medications, which aid in reducing the viscosity of the mucus produced in CF, have also had a considerable impact on CF management (Jones and Helm 2009). Bronchodilators are used to assist the airways and breathing and some improvements have been noted with the use of hypertonic saline prior to physiotherapy (Elkins et al. 2006).

1.8.4: Future Management

With advancements in technology, new medications are being introduced, but can be costly. An example of this is Ivacaftor™ (Kalydeco®), which is a CFTR potentiator, that has an effect on a selection of CF alleles ($\Delta F508$, R117H, G551D) (Flume et al. 2012). The cost of this drug is approximately £16,000 per month for each person (Kaiser 2012). Clearly ongoing research regarding the overall effects of this medication is needed (Flume et al. 2012) although anecdotal evidence suggests that some patients have improved symptoms and reduced hospitalisations since taking the drug.

Lung transplantation is the final level of management for a select number of young people with CF (Taylor et al. 2006, Geller and Rubin 2009) and although this does not offer a cure for the condition (Sweet 2009), it is a way of extending the lifespan for an undefined length of time (Doull 2001). Not all individuals with CF want or are able to receive a lung transplant and a considerable number of those who do opt for this method of management, will die before the donor lungs become available (Doull 2001). Statistics published by the UK Cystic Fibrosis Registry (2016) identified that in 2014, 247 individuals with CF were evaluated for a potential transplant and of these, 146 met the criteria. However, only five

individuals actually received donor organs, three of which, were liver transplants and two were bilateral lung transplants. In 2014, a total of 137 individuals in the UK with CF died, 93 of whom were in the 16 – 35 year old age group (UK Cystic Fibrosis Registry 2016).

Additionally, survival rates for lung transplants are not as successful as other organ transplants, possibly due to variable compliance with management (Nossent et al. 2009) and the actual survival benefit following a transplant is strongly debated (Walsh et al. 2009). As transplantation is not a 'cure' for CF, other avenues of management continue to be explored.

Since the discovery of the CF gene in 1989, the idea of using gene therapy to halt the progression of CF has been at the forefront of research (Jones and Helm 2009). However, to date the effects of the 'improved' CFTR have been limited and it is suggested that overall, continued improvement in CF management will be "not as the result of major technological breakthrough" (Doull 2001 p65) but by ensuring that individuals with CF maintain the best possible level of nutritional status and by averting the repeated lung infections that inevitably contribute to the mortality of individuals with CF (Doull 2001).

1.9: The Impact of CF on Adolescents and Families

The impact that CF has on the adolescent depends on the allele they carry and the severity of the condition. Potentially, the global effects of CF, which will eventually effect the majority of bodily systems, are considerable and some of the complications of this condition have already been outlined. Additionally, varying levels of malnutrition in childhood and adolescence affects growth, development and the onset of puberty, with the majority of adolescents having some level of growth retardation and a low body mass index (Wiehe and Amdt 2010).

As adolescents with CF continue to live longer, the ways in which they are affected from a psychological perspective continue to emerge. Furthermore, due to the complexity of their management regime and their overall health status, CF can impact on the individual's ability to leave home to attend university or obtain and / or maintain employment (Demars et al. 2011). This will inevitably impact on career choices, their future financial situation and social opportunities (Carsen and Voorhees Hieber 2001). Additionally, issues surrounding future health status, potential transplantation and premature death can cause considerable

psychological problems such as depression (Iles and Lowton 2008) for young people and parents (Havermans and Staab 2016).

Adolescents in general want to be the same as (or perhaps a little better than) their peers (Rice and Dolgin 2008). However, a condition such as CF with a persistent cough, a high calorie diet, periods of weight loss, increased offensive smelling flatus / stools and potential pubertal delay, singles them out from their peers (Harrop 2007). Additionally, periods of ill health cause absences from school, and this again makes the adolescent different and makes them 'stand out from the crowd' (Carsen and Voorhees Hieber 2001).

Consequently, CF has the potential to impact on the ability of young people to form relationships (Harrop 2007). Indeed, there is evidence that some young people will not disclose their diagnosis of CF to their friends, which makes peer support difficult (Badlan 2006). The development of peer relationships within adolescence is vital as not only do peer relationships provide companionship and a sense of belonging but they also foster increased levels of self-esteem, the development of social skills and an increased sense of well-being (Rice and Dolgin 2008).

When I first started working with young people with CF and their families, it was noted that, they formed tight knit peer groups and 'communities', which provided them with a considerable level of support. However, this ended abruptly when the potential for cross infection (Hockenberry et al. 2003) was recognised and, based on my own observation from practice, it became evident that this left adolescents and parents somewhat isolated and without the strong support mechanisms that they had previously been able to access. If adolescents are unable to develop and maintain peer relationships, it will also have the potential to impact on the formation of partnership relationships (Rice and Dolgin 2008). Adolescents who do not have good peer relationships can experience episodes of loneliness and isolation, which can in turn lead to psychological distress and depression (Harrop 2007).

The development of self-esteem and good social skills are also important as this will assist the adolescent in the transition process. Adolescents moving to adult services need to form 'partnerships' with health care providers in a new health care setting (Iles and Lowton 2010) and this is difficult if they have not developed

the skills to do so. Furthermore, this takes time and it is important that the formation of relationships with adult health care staff should be fostered within the transition process.

It has already been established that although the majority of individuals with CF are diagnosed within the first 12 months following birth, this is not always the case (UK Cystic Fibrosis Registry 2016). However, regardless of the age at diagnosis, it is suggested that when a diagnosis of CF is made, many parents actually move through a recognised grieving process as they grieve for the 'loss' of a normal child (Harrop 2007). Kübler-Ross (1997) identified five stages of the grieving process as denial, anger, bargaining, depression and acceptance. As individuals, both parents (where present) do not necessarily travel a parallel path on the grieving process. Parents of adolescents who have CF experience a range of emotions and although these may predominantly occur at the time of diagnosis the stages of grief are sometimes never resolved (Kübler-Ross 1997). This has the potential to cause marital disharmony, vulnerability, stress and anxiety, as well as physical and mental health issues (Streisand et al. 2001). Parents of young people with CF are very involved in their care and management and it is suggested that they can become overprotective (Bomba et al. 2016). Parents also form relationships with healthcare professionals within children's services. This has the potential to make transition equally as difficult for parents as for young people.

1.10: Transition

Due to improved technology and care, children with chronic illnesses such as CF are now living longer (Schwartz et al. 2014). CF is no longer viewed as an exclusive childhood condition but as a condition that is sometimes not diagnosed until adulthood (Gilljam and Björck 2004). Although the management of "adult pediatric patients" (Carsen and Voorhees Hieber 2001 p46) does occur, it is generally recognised that it is inappropriate for adults to be cared for by children's nurses and that a move from child to adult healthcare services is inevitable. However, this should involve more than just transferring the individual and their case history from one service to another. The way this move is undertaken has the potential to have a lasting impact on the adolescent and her / his parents and it is recognised that although a "smooth transfer" (Touchman et al. 2010 p 587) is desirable, this does not always occur (Crowley et al. 2011, Gleeson and Turner 2012).

However, the move from child to adult services should be viewed as more of a process than a transfer of location (Gleeson and Turner 2012) and in recognition of this, the term 'transition' has emerged. In 1993, Blum et al. on behalf of the Society for Adolescent Medicine (SAM) in North America, identified transition as:

the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health-care systems...[t]he optimum goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive.

(Blum et al. 1993 p570)

This has become the standard definition for transition (Viner 2008) and is referred to in the majority of publications pertaining to transition. Taking this a step further, Gleeson and Turner (2012) suggest that the process of transition is ongoing and does not only relate to the transition process itself, but that it needs to be judged by the health outcomes and continued engagement of the adolescent within the adult healthcare system.

To enable a successful transition, adolescents need to be provided with adequate preparation (Coleman and Berenson 2004, Shaw et al. 2004) and they need to be ready within themselves for the move from child to adult services (McDonagh and Viner 2006). If adequate preparation is not provided, the process can be problematic and stressful (Cowlard 2003, While et al. 2004). As this concept is the main focus of this thesis, transition will be discussed in greater depth within the literature review in Chapter Two.

1.11: Chapter Summary

This chapter has provided an overview of the research study including the primary research question. Background information was provided in relation to the three main themes from within this work. An overview of adolescence as a distinct construct and the influence that Grenville Stanley Hall had on this was identified. Discussion surrounding CF including, aetiology, diagnosis and management was included and the impact that CF has on the adolescent was highlighted. Finally, a definition of transition was provided. The key messages from this chapter are that:

- Despite some outdated views, G Stanley Hall is still credited as being the ‘father’ of adolescence and played a considerable part in developing adolescence as a construct.
- Adolescence itself is a transition period within the developmental process.
- Healthcare professionals working with adolescents need to have an understanding of the developmental process to enable them to provide appropriate levels of care.
- CF is a life limiting, debilitating condition for which there is no cure. Management is complex, onerous and the condition as a whole has a considerable impact on young people and parents.
- Young people with certain ‘childhood’ chronic illnesses are now living longer, which necessitates the transition of care from child to adult services.
- Wales provides a centralised service for child / adolescent and adult CF care.
- No specific research relating to CF and transition has been undertaken in Wales

1.12: Introduction to Individual Chapters

In Chapter Two, the search strategy and literature review for this study will be outlined. Relevant literature relating to transition and the provision of transitional services to adolescents with CF will be compared, contrasted and critically reviewed.

Chapter Three, will discuss the theoretical and methodological considerations that led to the structuring of this research including the Bridges Transitional Model that has been used within this study.

The methodology used within this study is interpretive phenomenological analysis (IPA) and this will be discussed in detail within Chapter Four. This chapter will

also identify the participant sample. The challenges encountered regarding the recruitment of participants will be identified, and the ways in which they were overcome will be outlined. Ethical considerations and issues surrounding researching with adolescents, will also be discussed.

Within Chapter Five, will present an overview of data management and chapters six and seven respectively will provide the findings of the data gathered from the young people and the parents through descriptive, idiographic, and conceptual analysis. Chapter Eight will discuss the linguistic analysis.

Chapter Nine will discuss the overall findings of the study and place these within the context of existing literature and Chapter Ten, the final chapter, will draw the thesis to a close, recap on the main discussion points and make recommendations for practice and future research based on the findings from within this work.

Chapter Two

A Review of the Literature

2.0: Introduction

The aim of this chapter is to contextualise the study within the existing knowledge base and it begins with a description of the search strategy employed. The most salient themes that arose within the current body of literature are then explored and critiqued and gaps in the literature are identified.

It will do this by critically reviewing the literature pertaining to the transitional care that adolescents with cystic fibrosis receive as they move from child to adult healthcare services. In general, the themes within the research literature are diverse with some research identifying the needs and concerns of patients and/or parents (Russell et al. 1996, Westwood et al. 1999, Brumfield and Lansbury 2004, Al-Yateem 2012). Some research identified issues from a provider perspective (Flume et al. 2004) and other research addressing specific areas such as preventative counselling (Zack et al. 2003), the most appropriate transition model (Madge and Bryon 2002), developing, making improvements to, or evaluating programmes (Nasr et al. 1992, Boyle et al. 2001, McLaughlan et al. 2008, Okumura et al. 2014) or changes in medical status during the transition process (Dugu  p  roux et al. 2008).

2.1: Search Strategy

An intentionally broad review of the literature was undertaken, due to the anticipated limited amount of empirical research in this area. Date parameters were not set and the literature specifically relating to CF and transition used within this literature review was published between 1992 and 2014. Additionally, as identified in Chapter One (pgs 4-5), research related to adolescence in general and CF transition specifically, is limited within the UK and a considerable amount of literature is published overseas. Therefore, the geographical location of the literature search was not limited to the UK, but broadened out to encompass other countries where CF centres exist such as the USA, Australia, and Europe.

From an initial scoping exercise it was noted that although there is a considerable body of available literature pertaining to CF and transition, this is predominantly in the form of commentaries, literature reviews and expert opinion. To support this,

the lack of specific CF transition research was highlighted in a systematic review undertaken by Doug et al. (2011), which focused on young people and their palliative care needs. However, because the literature relating to palliative care was also scarce, Doug et al. included a range of other health conditions, including CF. Doug et al. (2011) identified 31 studies relating to transition that met with their overall criteria, and although CF was recognised as the category that provided the “most studies” (Doug et al. 2011 p 167), only eight of the 31 studies they used related to CF.

The lack of empirical research literature was echoed by Fegran et al. (2013) who, in their metasynthesis, only identified 18 qualitative studies related to transition as a whole and only one of these related specifically to CF. All of the CF related studies identified by Doug et al. (2011) and Fegan et al. (2013) were reviewed as part of this literature review, although not all were critiqued in depth.

The databases used to retrieve the literature for this review included; the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database, British Nursing Index (BNI), Scopus and PubMed. Initially, the search included the key word ‘transition’ which yielded a total of 1,385,961 articles. The following key words ‘adolescent’, ‘adolescence’, ‘chronic illness’, ‘paediatric services’ and ‘adult services’ were then used in various combinations to filter the results this reduced the total number of articles to 691. The Boolean operator ‘AND’ was then used to combine a number of key words and the truncation sign (*) was used to shorten adolescence / adolescent (adolesc*). The American spelling of ‘pediatric’ was also used and no date parameters were set in an attempt to widen the search. Using all of the previous filters and then adding ‘cystic fibrosis’ finally reduced the total number of articles to 62 and selecting only ‘peer reviewed’ articles reduced this number to a total of 59 retrieved articles that appeared to be broadly relevant to the current study. An outline of the search strategy is provided in Table 2.

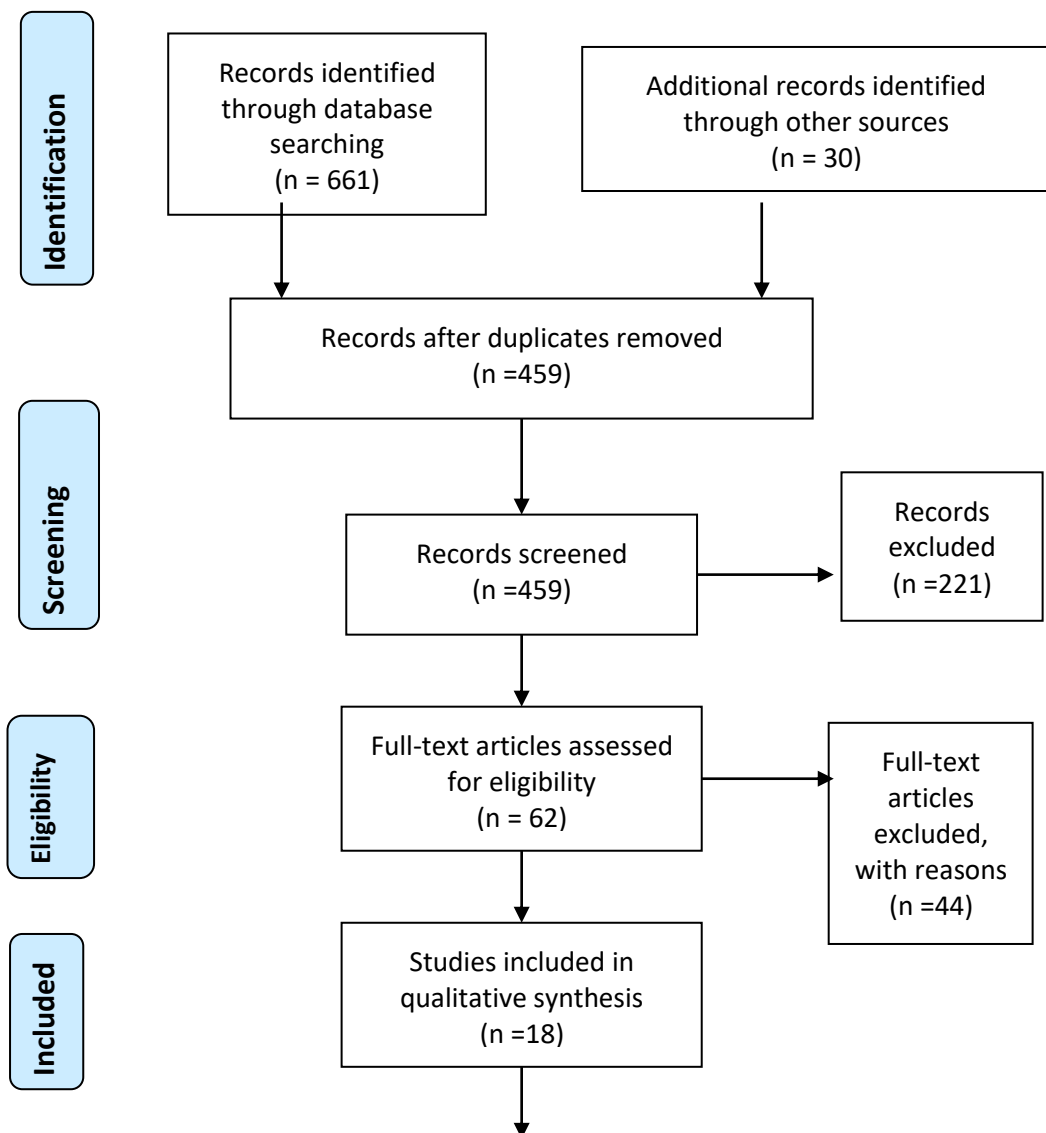
Table 2: Search Strategy

Initial search	Transitional care	691
Boolean operators Truncations	And chronic illness	221
	And children’s /paediatric / pediatric / adult services	
	And adaptation	
	adolesc*	
	And cystic fibrosis	62

Electronic data bases accessed	Cumulative Index and Allied Literature (CINAHL) Databases of the National Library of Medicine (MEDLINE) British Nursing Index Scopus	
Inclusion criteria	English language articles only. Peer reviewed journals. Primary research	59
Exclusion Criteria	Low quality Journals Transition not related to healthcare Studies related to CAMHS Studies related to adolescents with special healthcare needs Commentaries	
Back chaining	Back chaining of initial articles selected from electronic search allowing manual retrieval of books and articles relevant to the topic.	
National Publications	NMC / RCN / RCPCH (for guidelines) UK CF Registry	
	Final number of articles	22
	Following scrutiny of abstract and skim reading for relevance to topic	18

Although the use of key words was effective in reducing the overall number of articles, not all of the final articles (59) located through the search strategy related wholly to CF. As a consequence, all of the articles were scrutinised by reading the abstract and irrelevant articles were filtered out. For example, although some articles may have included CF in the title, little reference may have been made to this condition within the article itself. Alternatively, in other articles where transition had been explored in relation to a combination of chronic conditions, the number of CF participants included in the sample was so small that this was overshadowed by the rest of the participant groups. Therefore, the final articles were chosen due to their relevance to the subject of transition from child to adult services for young people with CF. The remainder of the articles were then placed into definite and potential categories for detailed reading and closer scrutiny. This is also identified below in the PRISMA Flow Diagram

Figure One: PRISMA Flow Diagram



Although the term ‘primary research’ had been used as a limiter within the search strategy not all of the retrieved 59 articles were research studies. Consequently, from reading the abstracts and initially skim reading the articles, they were further categorized into empirical research studies and ‘other articles’ which included literature reviews and commentaries. From this filtering process, the final 18 articles were selected. However, due to the limited research specifically relating to CF and transition, some of the chosen articles in this literature review do relate to other types of chronic illnesses and these have been used where relevant. The exception to this were transition articles related to child and adolescent mental health services, (CAMHS) and adolescents with special healthcare needs.

Due to the length of time taken to complete this study, the literature search itself has been ongoing. This is to ensure that up to date and current literature relating to CF and transition has been included. This practice led to the inclusion of the Al-Yateem (2012) and the Rutishauser et al. (2014) studies. Back chaining was also used as part of the literature search strategy.

As identified, the literature search retrieved a total of 18 articles that were believed to be appropriate to this study. Six papers were from the United States, five from the UK, two from Australia and one each from Ireland, France, Switzerland and South Africa. A study from Canada that explored CF and Spina Bifida together, was also included.

To review the research articles, the critical appraisal checklist as used by the Joanna Briggs Institute (JBI), (Table 3) an international collaboration of some 70 healthcare entities was used. Although the JBI's main focus is on the generation, synthesis, transfer and utilisation of evidence in healthcare (particularly regarding nursing and allied health practice) it does offer a range of checklists for a variety of different types of evidence quality. I selected the JBI Critical Appraisal checklist as it allows for a wider range of papers to be critically evaluated and, whilst it has its focus on healthcare, the checklist was helpful for studies from other disciplinary fields. The checklist seeks to establish three key concepts:

1. Congruity between philosophical position adopted by the study and study methodology; study methods; representation of the data; and interpretation of the results;
2. The degree to which the biases of the researcher are made explicit; and
3. The relationship between what the participants are reported to have said and the conclusions drawn in analysis.

Table 3 JBI Critical Appraisal Checklist

Criterion	Question(s)	Yes	Some	No
1. Congruity between the stated philosophical perspective and the research methodology	Does the report clearly state the philosophical or theoretical premises on which the study is based?			
	Does the report clearly state the methodological approach adopted on which the study is based?			
	Is there congruence between the two?			
2. Congruity between the research methodology and the research question or objectives	2 Is the study methodology appropriate for addressing the research question?			
3. Congruity between the research methodology and the methods used to collect data	3 Are the data collection methods appropriate to the methodology?			
4. Congruity between the research methodology and the representation and analysis of data	4 Are the data analysed and represented in ways that are congruent with the stated methodological position			
5. Congruity between the research methodology and the interpretation of results.	5 Are the results interpreted in ways that are appropriate to the methodology?			
6. Locating the researcher culturally or theoretically	Are the beliefs and values, and their potential influence on the study declared?			
7. Influence of the researcher on the research, and vice-versa, is addressed	Is the potential for the researcher to influence the study and for the potential of the research process itself to influence the researcher and her/his interpretations acknowledged and addressed?			
	Is the relationship between the researcher and the study participants addressed? Does the researcher critically examine her/his own role and potential influence during data collection?			
	Is it reported how the researcher responded to events that arose during the study?			
8. Representation of participants and their voices	Does the report provide illustrations from the data to show the basis of the conclusions and are participants are represented in the report?			
9. Ethical approval by an appropriate body	Is there a statement on the ethical approval process followed?			
10. Relationship of conclusions to analysis, or interpretation of the data	Are the conclusions drawn by the research based on the data collected (data being the text generated through observation, interviews or other processes)?			

Taken from the Joanna Briggs Institute Reviewers Manual (2014). JBI University of Adelaide

A sample of the way in which the appraisal tool was used based on the papers (Al-Yateem 2012) can be found in Appendix 1. Following the appraisal of each article and for my own ease of referral, the information was collated in a critical grid, the headings of which are loosely based on the JBI format (Appendix 2).

2.2: Summary

The review of the literature identified several key themes, which will now be examined further these were;

- Lack of adequate preparation prior to transition
- Issues for young people and their families
- Issues surrounding services
- Problems related to ineffective transitional care
- The role of the nurse in the transition process.

2.3: Lack of Adequate Preparation Prior to Transition

According to Viner (2008), transition should not occur until young people are ready and are able to manage the adult healthcare system. However, the author does not offer any definition of what being 'ready and able' actually is; and it can be argued that this would not only be different for each individual, but that readiness and ability would also occur within different time frames. Including young people in the preliminary preparation for transition would enable staff to assess the readiness of the individual for transition. It is important therefore, that the needs of young people transitioning to adult services are elicited and that young people are equipped with the skills to be able to manage the adult healthcare system, well before they are transferred to adult services. They also need to be provided with appropriate information about adult services.

There are fundamental differences between the way that child and adult services are managed. Family centred care (FCC) is considered to be "best practice" (Ahmann 1998 p 467) and parents are encouraged to participate in the care of their hospitalised child (Callery 1997, Shields and Nixon 1998, Lugasi et al. 2010). Consequently, the framework of children's healthcare is based around the interaction between healthcare professionals and parents as well as the child. As part of this overall process and care model, allowances are made and, for example, if children do not attend clinic appointments or fail to attend for routine hospital admissions, contact is made either by telephone or letter to enable rescheduling of dates.

In contrast, adult healthcare is more focussed on the user and the concept of patient-centred care, according to Kirk (2008) serves to minimise the role and input of the family. A statement supported by Iles and Lowton (2010) in their study which found that the exclusion of the family from care management means parents can no longer discuss results and other clinical information. Furthermore, parental time with medical staff is limited and parents are not able to have 'open

access' to their hospitalised adolescent (Reed-Knight et al. 2014). In addition, if clinical appointments are missed, adult services do not always follow up patients with some hospitals even operating a 'three strike' system, whereby if a patient misses three consecutive appointments they are effectively discharged. This system, Viner and Barker (2005) argue, does not fit well with the often chaotic lives of adolescents and while it is important that young people and parents are made aware of 'the rules' long before the move to adult services takes place, the very nature of this age group can find such regimens a challenge. The responsibility lies not only with young people (and to a lesser extent parents) as staff in adult services also need to take some responsibility by recognising that young people are new to the adult system and as a result they need to remind young people and parents of the way adult services are managed, thereby enabling them to follow 'the rules' (Wong et al. 2010).

The timing of transition is another important factor as without a time frame, it is difficult to set the process in motion and instigate appropriate planning. However, transition is often determined by the availability of beds within adult services and although targets relating to transition may be set, they may not be adhered to. Additionally, the appropriate age to transition young people and whether this should relate to chronological age or cognitive ability has been debated for some time (Reiss et al. 2005). An early study undertaken in Australia by Court (1993) was the first study to actually ask adolescents when they thought it was appropriate to transition. The study focused on adolescents with type 1 diabetes and the results indicate that the young participants felt that transition should not occur before the age of 17 years (Court 1993). This is, admittedly, a dated study but it does serve to make recognition of the length of time that, in contrast to the UK, improving transitional services has been at the forefront of adolescent healthcare in Australia for some time.

A more recent Swiss study by Rutishauser et al. (2014) undertook a cross-sectional study that used 28 set questions in a self-administered questionnaire, the aim of which was to elicit young people's experiences of transition, what they felt were barriers to transition and to determine an optimal age for transition. A total of 283 participants aged between 14-25 years of age completed the pre-transfer questionnaire but only 89 completed the questionnaire post transfer. The researchers accounted for the reduction in post questionnaire completion by indicating that some participants had become disinterested, while others no

longer considered themselves to have a chronic illness (Rutishauser et al. 2014). Results of the Rutishauser et al. (2014) study indicate that when both groups (pre and post) were combined, 80% of the participants believed that somewhere between 16-19 years was an appropriate age to transition and within this, more than 50% believed 18-19 years was the optimal age. The adolescents and young adults within the Rutishauser et al. study tended to favour a later transition, but the responses were varied indicating that even the individuals needing to transition are undecided themselves when this should occur. The Rutishauser et al. (2014) study used a range of young people and young adults with various chronic illnesses and although individuals with CF were included, the numbers were not presented in the results. Therefore, caution needs to be applied in suggesting that these results could be representative of any individual with CF. Additionally, neither study was undertaken in the UK, and although the Australian healthcare system is similar to that of the UK, Rutishauser et al. (2014) does identify that cultural differences should be recognised with regard to adolescents in various healthcare settings. To illustrate this, Rutishauser et al. (2014) highlight that in the USA for example, paediatric care continues until the age of 21 years, which is not reflective of other countries such as the UK, Australia or Europe. However, I would suggest that the issues for young people in relation to transition are similar across all western countries and as a consequence, the results of both studies could be applicable to young people within the UK setting.

Whilst the Rutishauser et al. (2014) paper provides a good insight into the preferred age at transition for young people, it does miss out some vital information. For example, other than suggesting that participants attended one of a range of identified clinics, the authors do not identify how the participants were recruited, whether ethical approval was sought, or what information the participants were provided with prior to commencing the study to enable informed consent. Interestingly, although the study was undertaken in Switzerland, one of the three authors was a recognised professor of adolescent health from Melbourne, but her role in this study was not made clear.

Regardless of the individual's age at transition, adolescents and parents need to be provided with as much information as possible prior to transition (Viner 2003) and this should be managed over a period of time. It is important therefore, that transition should be a well-co-ordinated, planned and unhurried process (Cowlard

2003) and although there is no fixed time for transition, (Viner 2003) young people and their families need to be ready for the process to take place.

In a UK qualitative study by Shaw et al. (2004), the importance of being adequately prepared before making the transition between services emerged as one of the key themes for discussion. Additionally, the change in care management from parent to adolescent was clearly identified as necessary but difficult (Shaw et al. 2004). The aim of the Shaw et al. study was “to gain an insight into the transitional needs of adolescents with juvenile idiopathic arthritis (JIA)” (p770) and although it was not identified in the title of the article, parents and partners also participated in this study. Shaw et al. (2004) provide a good overview of the study from recruitment to data analysis and a rationale is provided for the use of focus groups and this is congruent with the methodology for this study. Eleven focus groups were held with young people, young adults and parents across the UK with a total 53 participants, including 12 adolescents, 13 parents (plus one grandmother) of adolescents, 18 young adults, seven parents and two partners of young adults.

Although Shaw et al (2004) only focused on JIA as a specific chronic illness, there is no evidence to suggest that the experiences of young people with JIA and their families are unique to their condition or would differ greatly from young people with CF and their parents. The results reaffirm what is already known that making the transition between child and adult services can be problematic and stressful for adolescents (see Cowlard 2003 and While et al. 2004, for example); particularly so when they are not prepared appropriately for the transition process (Viner 2003). Consequently, young people may become anxious and resistant to the idea of moving to adult services. Healthcare providers need to be able to recognise the issues that are important to young people and their families to enable them to be appropriately supported during transition.

2.4: Issues for Young People and their Families

In relation to the transition process there are a number of issues for adolescents and parents that emerge from the literature, these predominantly relate to a limited level of preparation prior to transition. These include the challenge of changing caregivers, lack of involvement in the decision making process, lack of information sharing and communication and the concerns voiced at changing the actual location of care.

2.4.1: The Challenge of Changing Caregivers

Young people are often concerned about the services they will receive once they have transitioned, particularly regarding the clinics in adult hospitals. Many adolescents believe that the services will be “impersonal” and that staff will be “unfriendly” (Viner 2003 p.210). Transition can be a significant event in the lives of adolescents as they are forced away from people who they know, trust and respect, towards people they do not know and, as a consequence, may have difficulty in developing a trusting relationship. This can lead to a lack of confidence by both adolescents and their families and in certain situations, as Viner (2003) suggests some parents may “sabotage” (p2685) the transition process to prevent it from occurring. This is particularly applicable to parents who do not understand the need for transition or if they are not included in the decision making process regarding the transition between services.

A study undertaken in the USA by Zack et al. (2003) identified the concerns of individuals with CF moving from child to adult care. This mixed methodological study with a total of 32 participants aged between 16-46 years used face to face 30 minute interviews to work through a set of 23 structured questions prior to completing a 30 question self-administered questionnaire. However, only eight of the questions within the questionnaire were open ended. Given that Zack et al. wanted to gain the perspectives of their participants, their method of data collection was interesting and although the authors provide no rationale for their choice, they do identify that it was part of a larger study. Although the qualitative aspect of the study captured the participants own experiences of transition and this is clearly represented in the article with verbatim quotes, with only eight qualitative questions. Additionally, the age range of the participants in the Zack et al. study is particularly diverse and, developmentally, the responses of the participants to the structured questions could have been equally as diverse. Therefore, it could be argued that although the structured questions standardised the procedure, this may not have been the best method of data collection for this study.

Zack et al. (2003) identified that there was no transition service at the hospital where the study was undertaken so it is not clear from the article at what age patients were expected to transition, or indeed how many of the participants had actually made the transition to adult services. However, it was noted that only 11 of the 32 patients “had considered transferring their care” (Zack et al. 2003;

p380). Furthermore, one participant indicated that due to being dissatisfied with the care in adult services, the participant had returned to the children's hospital for their care provision. These are interesting comments given the upper age limit of the participants. However, these comments are the opinions of participants in one particular setting and caution needs to be taken in attempting to apply them to a UK setting, particularly as in the UK, it is suspected that in the majority of situations, individuals would not be accepted back to children's services once they had made the transition to adult care. It is possible that the comments are reflective of the fee for service system in the USA, which would appear to allow patients to choose their location of care. This also has considerable implications for the housing of younger adolescents (technically minors) and adults together when paediatric care continues until the age of 21 years in the USA (Rutishauser et al. 2014) and Zack et al. (2003) have not identified how this situation is managed.

Although the Zack et al. study adds to the body of knowledge related to transitional care, it does have limitations, some of which are identified by the authors. One of the limitations noted was the "small sample size" (Zack et al. 2003 p381), which again suggests that researchers were leaning more towards the quantitative as opposed to the qualitative aspect of their study.

In an Australian qualitative study, Russell et al. (1996) developed an interview guide using the key components of the Roy Adaptation Model (Roy 2009). The rationale provided by the authors was that there needs to be a "continuing process of individual adjustment to any situation" (Russell et al. 1996 (p263) when any change occurs, the change in this instance being the transition from child to adult services. Seven young people with CF and eight parents participated in the study, all of the young people were aged between 11 – 20 years and all needed to have undertaken the transition process to be eligible to participate in the study. Data were collected via semi-structured interviews, using open ended questions and the interview guide was piloted prior to the commencement of the study. Russell et al. (1996) analysed the young people's results through the Roy Model based on a developmental perspective and viewed their unaccompanied attendance at adult CF clinics as part of the process for developing identity, autonomy and taking control of their own condition, which is a logical assumption. However, in relation to the parents, the results indicated that the parents in particular felt abandoned by paediatricians and excluded by

adult physicians (Russell et al. 1996). For parents who have cared for their chronically ill child since birth, this must be extremely difficult to contend with and as Russell et al. (1996) suggest, the transition from child to adult services for adolescents, also provokes a transition period for parents, whereby there is a relinquishment of parental responsibility and a transfer of total self-care to the adolescent. This is an important issue for parents and one that I identified within my own study and ultimately drove my decision to include parents as a participant group.

The promotion of self-care is a major goal of adolescent management, but it is important to remember that transition often occurs at a time when neither the adolescent nor the parent are prepared for the transfer of care management from parent to adolescent. This is particularly so when there are unresolved concerns relating to transition. Although the Russell et al. (1996) study is quite dated, there is no recent evidence to suggest that the views of parents have changed, indeed in part it is supported by the results of this current study and as a consequence, the results could be easily transferred to a UK setting.

In a small quantitative study from the USA by Boyle et al. (2001), a pre and post transition survey was undertaken to determine participants' views on transition. A total of 52 adolescents and 38 parents participated in the pre transition survey and 60 adolescents participated in the post transition interview / survey. The average age of the participants was 29 years, but despite Boyle et al. stating that demographic data had been obtained, very little additional information was provided about the participants in this study. The study identified several key areas of concern for both adolescents and their parents related to the transition process, which included; leaving behind and having to meet new care givers, and that the adult team would not be as caring. Although, this last point was not their main concern, it did feature as the third most reported concern (Boyle et al. 2001). Despite this study being identified as quantitative in nature, with the results being presented in statistical format, much of the data were obtained by face to face or telephone interviews, which is more in keeping with a qualitative research design. However, as the interviews were structured with pre-determined questions, Moule and Goodman (2009) identify this as an appropriate method of quantitative data collection. The researchers indicate that the rationale for undertaking this study was due to the increasing survival rate of young people with CF and all participants were recruited via the Johns Hopkins CF clinics in

Baltimore. Data analysis is consistent with a quantitative research methodology and the results are presented statistically using discussion and charts to report these. The results of this study are consistent with literature from the UK pertaining to transition, (Viner 2003, Shaw et al. 2004) thereby making it relevant to include in this study.

2.4.2: Lack of Involvement in the Decision Making Process

Ideally, within adolescent care, parental involvement should decrease, whilst the involvement of the adolescent in their own management should increase. However, involvement by both parents and adolescents appears to dissipate during the transition process. Part of the reason for this is a lack of structure to the process of transition, particularly in relation to the age when transition occurs, and the varied level of pre-transition information provided to young people and their parents.

Adolescents are 'transferred' to adult services for a variety of reasons including age, leaving school, pregnancy, self-harm and non-adherence to management regimes (Viner 2001a). In most instances age appears to be the predominant factor, although this again is variable. Some paediatricians are able to employ some level of discretion in relation to the age of transfer while others are confined by the insistence of the hospital trust policies to transfer patients automatically once they reach their 16th birthday (Webb et al. 2001). Despite the growing body of literature regarding transition, evidence still suggests that there are young people who do not have the opportunity to discuss their impending transition prior to it occurring, (Anderson et al. 2002), which leaves many feeling inadequately prepared (Tuchman et al. 2008). Furthermore, there are some young people whose only method of transition preparation is a letter to them closely following their 16th birthday informing them that their service provision has changed (Shaw et al. 2004). This is particularly relevant as it is noted that some adolescents are not ready developmentally or emotionally to take on the full responsibility of making hospital appointments and managing their care themselves (Westwood et al. 1999). It is important therefore that the adolescent developmental process is taken into consideration when transition is being considered (Westwood et al. 2014).

Gaining the opinions of young people regarding when transition should occur is important in order to facilitate improvements in service provision. Westwood et al.

(1999) undertook a cross sectional survey in South Africa (SA) to determine the perspectives of young people with CF and their parents, some of whom were awaiting transition and others who had already made the transition to adult services. Sixty one semi-structured questionnaires were mailed to potential participants and these were separated into adolescent and parent groups. A covering letter stating that participation was voluntary was included with the questionnaires and the return of the questionnaire (77% response rate) implied consent (Westwood et al. 1999). Although this would be considered to be a small quantitative study (N=47), the numbers of individuals with CF in SA is limited in comparison to other countries such as the USA, Australia and the UK. However, the researchers included all of the eligible adolescents and adults within their particular CF centre, so the sample is representative of their target population. As part of this study, participants were asked to identify the youngest and oldest age when transition should occur. Both the parents and young people in this study determined that somewhere between 16-18 years of age was the optimal time to undertake the transition process. This age range concurs with findings from a range of studies (Court 1993, Rutishauser 2014) including a USA study by Flume et al. (2001), which surveyed paediatric and adult programme directors at the main CF centre in North America and determined that 18 years of age was the optimal time for transfer (Flume et al. 2001). Therefore, there is nothing to suggest that transition within the 16-18 year age range could not be appropriate to the CF setting in Wales.

In the 2004 qualitative UK study by Shaw et al. examining the perspectives of individuals with juvenile idiopathic arthritis (JIA), four focus groups were used to gain data from: (i) adolescents aged between 11-18 years with JIA; (ii) their parents; (iii) young adults aged between 19-30 years and; (iv) their parents. Recruitment to the study was justified with a clear rationale for the selection process and written consent was provided by all participants. The total number of participants in this study was 53 and it also included the spouses of two of the older participants with CF. In this study, each of the focus groups were provided with a set of questions to facilitate discussion. Each audio taped focus group lasted 120 minutes. The audio tapes were transcribed verbatim and interpretive phenomenological analysis (IPA) was used to interpret the data (Shaw et al. 2004). Although IPA is congruent with the overall aim and methodological approach for this study, Shaw et al. (2004) do not describe the IPA process in any detail and, without some prior understanding of IPA, the analysis section is a

little difficult to follow, particularly in relation to recognising how IPA differs from thematic analysis (Smith et al. 2009) in this context.

The study by Shaw et al (2004) did not identify a specific time frame for making the transition between child and adult services, but it did recognise the value of support from staff during the process. Furthermore, the anguish and emotional cost to the adolescents and their families brought about by an abrupt, unplanned transfer with little or no consultation was evident. This further highlights the need for adequate preparation, information sharing and involvement in the decision making process. Although Shaw et al. did not include adolescents with CF, many of the issues raised within this study are not condition specific and could be equally applied within the context of CF and transition.

Providing adolescents with an opportunity to be involved in making decisions about their own care promotes the development of autonomy (Westwood et al. 1999), which is paramount in their management (Rice and Dolgin 2008). Furthermore, as Thompson et al. (2000) point out, promoting autonomy is enmeshed within ethical principles and recognition of basic human rights. However, to enable adolescents and their families to make informed choices and thereby promote the development of autonomy, it is important to provide an appropriate level of information and employ effective communication strategies.

2.4.3: Lack of Information Sharing and Communication

The lack of information and knowledge about CF that some adolescents with this condition have, was a concern noted within two of the reviewed studies (Westwood et al. 1999, Boyle et al. 2001). Whilst it is recognised that these studies are dated, again there is no real evidence to suggest that the situation has improved, particularly as parents continue to be the main caregivers throughout childhood and well into adolescence. However, adolescents need to have an understanding of their condition and their management programme, in addition to recognising their changing symptoms and potentially deteriorating condition to be able to seek appropriate help when necessary from the relevant health professionals (Viner 1999). Consequently, part of the transition preparation process should include age appropriate information that enables the adolescent to increase their knowledge regarding their condition and its management.

The USA based researchers Anderson et al. (2002) undertook a quantitative international study whereby 1,288 self-administered questionnaires were

distributed through the International Association of Cystic Fibrosis Adults (IACFA). A total of 334 questionnaires were returned indicating a poor response rate of 25.9% and included participants from the USA and “25 other countries” (Anderson et al. 2002, p328). However, it is not clear which countries actually participated in this study as not all were identified and only four countries other than the USA were named. The USA recorded the largest number of responses (n=200), mainland Europe (n=43), the UK (n=24) and Australia/New Zealand (n=43). The participants in this study were predominantly adults with a mean age range of 34.5 years although 10 participants were under the age of 18 years. The Anderson et al. study was in fact the second part of a larger study (Flume et al. 2001), which had sought the experiences of CF physicians on the transition process. Following the completion of both studies analysis of variance (ANOVA) statistics were undertaken to make comparisons between the young people’s results and those of the physicians from the previous study (Flume et al. 2001). Although the overall findings for this study suggested that participants did not have any major concerns regarding the transition process, just over half (59%) indicated that they had been concerned about assuming a greater responsibility for their own care. Although the UK was included as one of the countries in this study, the limited information about the participating centres does not identify whether or not the Wales CF centres took part. However, it is justifiable to suggest that results from this study could be applicable to CF care in Wales.

Several studies (Westwood et al. 1999, Boyle et al. 2001, Flume et al. 2001) found that parents had major concerns regarding their adolescent’s ability to manage their own CF care, although it did not always appear that the adolescents voiced the same concerns as their parents. This could be a reflection of the parents’ concerns about ‘letting go’ as they work their way through their own form of transition process that ends by relinquishing care to the adolescent (Westwood et al. 1999). Whatever the reason, these are real concerns for parents and need to be addressed.

Moving from child to adult services for some adolescents and their families can be described as stepping into the unknown. If transition does occur suddenly, with limited preparation and planning, adolescents and their families can be launched into a new service without knowing what to expect.

Boyle et al. (2001) found that adolescents and parents voiced particular concerns about infection control issues in adult hospitals. As many individuals with CF colonise *Burkholderia Cepacia* and / or *Pseudomonas Aeruginosa* in their lungs, the way this is managed in an adult setting is an important issue for adolescents and their parents. The two stage quantitative study by Boyle et al. (2001) was undertaken in Baltimore in the USA and involved a total of 80 'adults' (defined as over 16) with CF. The participants completed a self-administered anonymous questionnaire three months prior to transition and then a post transition interview one year following transition. The authors, do not specify whether the participants needed to move to another hospital or whether child and adult services were located at the same site. This last point is an important consideration as concerns voiced by adolescents regarding infection control suggest that the adult service was not necessarily in the same hospital, otherwise infection control procedures should have been consistent. Conversely, if both child and adult services were on the same site, participant comments related to concerns about infection control procedures have implications regarding a potential inadequate level of communication between services.

2.4.4: Changing the Location of Care

Transition often necessitates the move to a different hospital, so the young person would need to alter travel routes and make alternative travel arrangements, which can pose additional problems related to time and cost. For adolescents who are transitioned between departments but in the same hospital, accessing the hospital may be the same but manoeuvring through the system may be different and adolescents and their parent/s have to learn new ward 'rules and regulations', which can often be less flexible than they are accustomed to. Consequently, many of the concerns regarding the changing location of care relate to previous discussion under subsection 2.4.1.

However, one of the most noteworthy issues that the transfer from child to adult services does highlight, is that the adolescent will inevitably come into contact with adults who are at a more advanced stage in the disease process (Madge and Bryon 2002). This has the potential to force adolescents to confront their own mortality (Russell et al. 1996), which may be something that they are not ready to do or had not even thought about (Bill and Hodges 2007). This is an issue of concern for both parents and adolescents and was identified in the Australian study undertaken by Russell et al. (1996) in which, parents described their fears

in relation to confronting the death of their child. Some participants in the study chose to share how they felt when their friends died and suggested that on a personal level it made them feel that they did not want to go back to the adult hospital (Russell et al.1996).

In an audit of an adolescent transition service provided at a large London based hospital undertaken by Madge and Bryon (2002), adolescents identified that they considered becoming an adult and moving to adult services equated to imminent death. Although this quantitative survey is not strictly 'empirical' research, this should not detract from the concerns voiced by adolescents relating to the way they view adult services and their expressed feelings of vulnerability and lost security. However, the Madge and Bryon (2002) paper is dated as improvements in lifespan for individuals with CF have seen increasing numbers surviving into adulthood (Iles and Lowton 2010). Despite this, time has not necessarily ended the myth amongst young people that transition equates to dying and as some young people with CF still die in adolescence (UK Cystic Fibrosis Registry 2016), the myth is reinforced as 'fact'.

This issue highlights the complexity of adolescent management and the transition process, as the association between other discussion threads within this chapter become enmeshed. Lack of involvement in the decision making process related to transition, lack of information sharing with the adolescent and their family and the lack of preparation for transition have the potential to exacerbate feelings of vulnerability and insecurity voiced in the Madge and Bryon (2002) audit. Furthermore, young people who are striving to gain autonomy take responsibility for their own care and come to terms with 'adolescence' as a whole, may not be able to manage the additional confrontation of accepting their health status and as a consequence, disengage with service provision (Viner 2008). This can have a considerable impact on the adolescent as a whole and will be discussed in more detail later in this chapter. It also highlights that the timing of transition is imperative and that on occasion, depending on the health status of the individual, with consultation and discussion with the family, transition to adult services may not be the best option.

2.4.5: Continued Parental Involvement

One of the main aims of pre-transition preparation should be to facilitate self-management skills in the adolescent (Sharma et al. 2014), however, this does not mean that the role of the parent does, or should, cease at the point of transition. In a UK study undertaken by Iles and Lowton (2010), 50 young people with CF and 23 healthcare professionals from two CF centres in England were interviewed to determine the perceived nature of parental support for young people with CF. Recruitment was through the CF clinic with letters and an information leaflet sent by the clinic staff, thereby removing the researchers from the process. Interested individuals made contact with the research team and informed consent was obtained (Iles and Lowton 2010). Data were collected via semi-structured interviews, which were then audiotaped and transcribed verbatim and a thematic approach was used to analyse the transcripts (Iles and Lowton 2010) all of which are consistent with a qualitative research methodology. In this study, young people recognised the continuing role in their care by their parents and the level of support this provided. However, the conflict this caused with staff within the adult healthcare setting was also noted (Iles and Lowton 2010). The support provided by parents included; practical and emotional support, acting as advocates and stepping into resolve specific issues as they arose and continuing to assist with home management. The fact that their parents also tried to shield them from difficult situations such as the life limiting nature of CF was also recognised. As such, the young people viewed their parents more as partners in care, a situation they were comfortable with, recognising that this would change over time as they became more used to adult services (Iles and Lowton 2010). This would seem to be a sensible approach to the transition process, and is particularly relevant if transition has been undertaken fairly swiftly. It is unrealistic to expect young people to take over their full management requirements at the point of transition, and it is also unrealistic to expect parents to terminate care at a specific point in time. However, it was noted that this was an area that caused conflict with adult healthcare providers, as although young people may view their parents as partners, it did not necessarily follow that this was the case for healthcare staff (Iles and Lowton 2010).

Iles and Lowton (2010) identified that this was a particular area of concern and tension for staff. Although it was recognised by staff, that parents *could* be partners in care, the belief that parents no longer had *the right* to information

because transition had occurred and the idea that the young person was now an adult and therefore autonomous, was entrenched in their practice. As a consequence, confidentiality 'overruled' and as such, parents were excluded from decision making, which in some cases, was against the wishes of the young person. This is a difficult situation for all parties and is one that may not be easy to resolve without a review of the current healthcare practices for young people. However it does link with discussion in section 2.4.1 in relation to learning 'the rules' in the adult setting as again the differences in management styles between FCC and self-care are highlighted. It is suggested therefore that there is need for a hybrid model of care that encompasses aspects of FCC and self-care that could be used in the management of adolescents in both the child and adult setting.

2.5: Issues Surrounding Service

Within the UK the provision of adolescent services as a whole is limited in comparison with countries such as the USA and Australia (Viner 2001a). Without a generalist base from which specialist services can be formulated, it is not surprising that adolescent transition services are also in many cases, ineffective and unacceptable (Viner 2001a). Furthermore, Cowlard (2003) recognises that there is little empirical research available and questions the issues related to the provision of transition services, although there are recognised barriers inhibiting the transition process. Adolescents, parents and healthcare professionals can view transition in negative terms as it raises concerns relating to the ongoing level of care they will receive from adult staff and many feel that making the transition between services will result in a reduction of care (Boyle et al. 2001, McDonagh et al. 2005).

In relation to service provision, the aim of an early quantitative study by Nasr et al. (1992) was to evaluate an existing transitional programme at one CF Centre in the USA. This according to the authors, was the first study to evaluate a transition programme and it is therefore important to include it in this review. The date of this study also serves to identify the lag in UK adolescent services in comparison to the USA as clearly transition programmes were in place in the USA over 20 years ago. The study undertaken by Nasr et al. (1992) involved gathering data via self-administered questionnaires from "adolescents and young adults with CF" (p682).

Of the 49 returned questionnaires, the majority (65%) felt that the adult setting was more conducive to their needs. What is interesting in this study is that seven of the participants clearly identified a more “aggressive” (Nasr et al. 1992 p684) level of management at the adult centre. It is possible that this occurred due to the deteriorating condition of the participants, particularly as the average survival age in the USA for young people with CF in the 1990s was 28 years. Indeed, Nasr et al. (1993 p683) identify that “two patients died during the time of the survey”. Therefore, caution needs to be applied when reviewing and attempting to apply the results of this study in any contemporary setting. Firstly due to the age of this seminal work and secondly, as it is no longer reflective of the survival rate of individuals with CF.

2.6: Reduction in the Quality of Care

Three main areas emerge from the literature in relation to a reduction in the quality of service; the inability of paediatricians to relinquish care, lack of appropriately educated staff and lack of educational opportunities for staff. All of which are interrelated but will be discussed individually in more detail.

2.6.1: The Inability of Paediatricians to Relinquish Care

One of the areas highlighted in the literature as being problematic is the suggestion that paediatricians have difficulty in relinquishing the care of their adolescent patients to adult physicians (Viner 2001a, Cowlard 2003). This phenomena is not confined to the transition of adolescents with CF. Binks et al. (2007) undertook a systematic review to determine what was known about the transition to adult healthcare for adolescents with cerebral palsy and spina bifida. A total of 149 articles were reviewed, four of which included a range of conditions such as diabetes, congenital heart disease, epilepsy and CF. Binks et al. (2007) concluded that many of the barriers to transition were similar across all conditions, with the first barrier presented for discussion being the inability of paediatricians to “let go” (p1065).

The issue of relinquishing care was further identified in a qualitative study from Australia undertaken by Brumfield and Lansbury (2004). This study involved in-depth face to face interviews with six individuals with CF aged between 19 to 34 years from the Sydney / New South Wales area. Although it was not the intention to have such a wide age range of participants, it was identified that problems with recruitment had led the researchers to widening the age criteria. The researchers

provided a clear rationale for undertaking the study and for using their chosen methodology. The interviews were audio- recorded, transcribed and thematic analysis was used to analyse the data, all of which is congruent with a qualitative research approach. Participants in this study clearly identified the close bonds that had been developed over time with paediatric staff, and through patient quotes Brumfield and Lansbury (2004) were able to highlight the impact the paediatricians attitude had on the transition process, and how this reflected on their ability to let go. For example one participant indicated that their paediatrician had not instigated transition “until he really had to” (Brumfield and Lansbury 2004 p227).

This is not an uncommon situation and the issue of relinquishing care has and continues to feature heavily in CF literature (Rosen 1995, Viner 2001a, Madge and Bryon 2002, Cowlard 2003, Flume 2009). Some paediatricians do appear to be reluctant to instigate their patients’ transition between services and there are a variety of reasons for this. Individuals with CF are in the main, diagnosed soon after birth. It is a life-limiting condition that needs close monitoring and, at times, intensive management. Consequently, paediatricians and other healthcare providers within the multidisciplinary team (MDT) work closely with children, young people and their families to maintain the wellbeing of the individual from infancy to adolescence or in some cases young adulthood (Brumfield and Lansbury 2004). It is understandable therefore, that supportive, trusting, long term relationships are formed and it can be difficult for healthcare providers as well as parents and adolescents to relinquish these.

Paediatricians are often ‘targeted’ as being barriers to the transition process (Flume 2009, Cowlard 2003) as it is generally the paediatrician who has the ‘authority’ to instigate the process (Brumfield and Lansbury 2004). It is easy to take this at face value and criticise paediatricians for not wanting to ‘let go’ of their patients and as Viner (2001) identifies, the impact of this should be recognised and not underestimated. However, concerns relate to more than breaking bonds with patients and historically, paediatricians have had valid reasons, on which to base their concerns.

2.6.2: Lack of Appropriately Educated Staff

CF was traditionally considered to be a childhood condition (Hodson 2000) but this situation has changed dramatically over the past 40 years and individuals

with CF are living considerably longer (Flume et al. 2001, Viner 2008). Improvements in management programmes have increased the potential life span of babies born in the 21st century to approximately 50 years of age (Duguépérroux et al. 2008) and CF is, also rapidly becoming an adult condition (Simmonds et al. 2009). However, the education of physicians (and other healthcare providers) has not necessarily kept up to date with this change (Gleeson and Turner 2012). Whereas, some paediatricians have increased their knowledge to encompass adolescent care, some adult physicians have a limited knowledge of 'childhood conditions'.

There is limited empirical research related to CF and the educational needs of adult physicians. However, in relation to chronic illness in adolescents in general, it is noted that appropriately educated adult focused healthcare providers are limited and that some physicians are reluctant to manage young people with long standing childhood conditions (Lotstein et al. 2005). This is identified by Peter et al. (2009) who undertook a quantitative study in Pennsylvania USA to determine the concerns of adult physicians, in relation to the transition from child to adult healthcare services of adolescents with previously diagnosed childhood conditions. A total of 241 physicians were randomly selected from the American Board of Medical Specialties Directory (Peter et al. 2009 p 417). From this number only 134 were deemed eligible (those who dealt with transitioning patients) to participate in the study and only 50% (n=57) actually completed the surveys. It is not clear why the response rate was low although this is recognised by the researchers under the limitations of the study discussion. The researchers also raise concerns regarding selection bias, which could have adversely influenced the findings of the study. In this instance, the researchers suggest the possibility that only physicians with an interest in adolescent health responded to the questionnaires and this may be a relevant comment. Additionally, the researchers widened the numbers of pages they reviewed in the American Board of Medical Specialties Directory to include more female physicians in their sample. However, findings from the study indicate that two of the main concerns identified by physicians were the lack of education in childhood conditions and the lack of education in the management of adolescent psychosocial needs (Peter et al. 2009).

Parents are often aware that adult physicians do not have the same level of knowledge regarding CF as paediatricians (Boyle et al. 2001) and this has the

potential to increase their anxiety regarding transition. Coupled with the concern of the paediatrician, this poses a considerable barrier to transition and can impede the process overall. The issue here however, is not to apportion blame but to move forward to progress the services provided for adolescents. Therefore, physicians with limited knowledge of childhood conditions and / or adolescent health need to be able to access the education they need to enable them to provide the required service. This is often problematic in itself.

2.6.3: Lack of Educational Opportunities

Whilst the need for adult physicians to gain knowledge in childhood conditions is recognised (Boyle et al. 2001), education in the needs of the adolescent is also required (McDonagh 2005, Por et al. 2004, Gleeson and Turner 2012). Viner (1999, 2001, 2008) is particularly disparaging of the level of adolescent health education available for physicians in general and suggests that the education of physicians within the UK remains focused on the younger child although he does concede that changes are being made to medical curricula under the guidance of the RCPCH (Viner 2008). The development of adolescent related education for HCPs is vital as if HCPs do not have an understanding of the needs of the adolescent; the ability to develop age appropriate programmes and management strategies is impeded (Gleeson and Turner 2012). This includes the development of transition programmes.

McDonagh et al. (2004) undertook a UK based quantitative study to determine the education and training requirements of healthcare professionals involved in providing transitional care. The study was part of a large multi-centre project and a total of 262 questionnaires were distributed to participants, these included medical consultants, programme co-ordinators, clinical nurse specialists, occupational therapists and physiotherapists. Responses from the questionnaires indicated that 114 (43%) of the participants identified educational needs related to adolescent care and management. Although this research focuses on JIA as a specific condition, the researchers relate their overall discussion on education and transition. It is easy therefore to replace JIA with CF in this research as the situation in relation to overall adolescent health knowledge / education and transition is the same. Thereby making this research applicable to the adolescent population with healthcare needs as a whole and in particular, those living in Wales.

However, it should be remembered that although improving educational opportunities in adolescent health is paramount, having an 'interest' in adolescents and their needs is also vital (McDonagh 2007). This may alleviate the perception of parents and adolescents that adult healthcare professionals are uncaring (Viner 2003) and improve the effectiveness of transitional care.

2.7: Problems Related to Ineffective Transitional Care

Transitional care should provide a smooth interface between child and adult services although for a variety of reasons, transition is not always successful. Consequently, an ineffective transition experience has the potential to have a lasting impact on the adolescent and her / his family. McDonagh and Viner (2006) suggest that ineffectively co-ordinated transition can result in an increased level of non-compliance with follow up appointments and management. This in turn has the potential to have an increased adverse effect on morbidity and mortality (Viner 2008). However, this is not always the case.

Duguépéroux et al. (2008) undertook what they identified as the first study of its kind. The aim of the study was to ascertain what clinical changes, if any, occurred during the transition from child to adult services. Their study, undertaken in France, involved a retrospective survey of patients received from one of the three paediatric CF centres in Paris. Data collection was thorough and collected at three specific points related to adult CF clinic attendances at the receiving hospital. Strict sorting of patients occurred based on their genotype, pancreatic sufficiency / insufficiency, pulmonary function tests for forced vital capacity (FVC) and forced expiratory volume in one second (FEV1) and body mass index (BMI) (Duguépéroux et al. 2008). In addition to this, information was collected on co-morbidities that are common to CF, such as diabetes mellitus and liver cirrhosis. A total of 68 patients (36 F / 32 M) participated in the study, with a median age of 21 years. The justification of the researchers for undertaking the study was in recognition of parental and paediatricians concerns regarding a perceived deterioration in health in individuals with CF following transition.

The main results from this study suggested that there was no increase in bacterial colonisation of the lungs and that the number of admissions to hospital did not increase in the first year following transition (Duguépéroux et al. 2008). Reductions in the main pulmonary tests forced vital capacity (FVC) and forced

expiratory volume at 1 second (FEV1) were noted, although the researchers suggest that these were within expected levels (Duguépéroux et al. 2008).

An additional finding to this study was that following transition, adolescents had increased their level of autonomy and management of their own condition (Duguépéroux et al. 2008). This is not an unsurprising find, given that parental involvement following transition is curtailed. What is not made clear is how the adolescents had achieved this autonomy and whether it was due to the overall adolescent developmental process, whether it had occurred with support, or whether it was due to a forced necessity (the 'sink or swim' option). Although the data collection method suits the methodology of this study and is appropriate to answer the researchers' questions, providing an opportunity for the participants to speak about their transition experience may have answered this question and also added another dimension to the study's results. Despite this, the study clearly adds to the body of knowledge surrounding transition and the results could be transferred to a UK setting. It would be interesting however, to see this study replicated within the UK with a wider range of participants, which could potentially encompass those who were not so well medically at the point of transition.

Duguépéroux et al. (2008) clearly reports on a successful transition programme and the researchers comment that their positive results are probably reflective of the participants' "stable condition" (p5) and readiness to make the transition. It could also be reflective of the participant's cognitive developmental level. In the Australian study by Brumfield and Lansbury (2004) they noted that participants who were most accepting of the transitional process and the changes between child and adult services appeared to be developmentally mature enough to cope with this. Conversely, the participants who had a more negative transitional experience and who had difficulty coming to terms with the process and the adult care setting, did not appear to be as developmentally mature (Brumfield and Lansbury 2004). This is an important point and one that needs to be taken into consideration when transition services are being planned.

Evidently the interface between the child and adult services in the Duguépéroux et al. (2008) study was efficient and worked well. This however, is not always the case and handing over patients between services can be problematic (Tan and Kilmach 2003) where full reassessments are undertaken (Viner 2001a) and tests

are repeated unnecessarily. This re-enforces the fact that open channels of communication are vital and need to be fostered and maintained between child and adult services (Madge and Bryon 2002).

2.8: Addition to Literature Review

It was noted earlier in this chapter that due to the length of time taken to complete this study, the literature search itself has been ongoing. Therefore, following the process outlined in the search strategy, Section 2.1 and the key words within Table 2, a final literature search was undertaken following examiner feedback to identify any literature published between 2014 and 2019.

As with previous literature searches, no literature relating to CF and transition undertaken in Wales was retrieved. However, in relation to the overarching themes of CF, transition experiences and information needs prior to transition, outlined within this literature review, some recent literature was retrieved. Fourteen articles related to a range of issues regarding transition and CF were accessed. These included three qualitative studies (Aldiss et al. 2015, Bourke and Houghton 2018, Fixter et al. 2017), three quantitative studies (Sawicki et al. 2017, Bowmer et al. 2018, Coyne et al. 20018), one mixed methods study (Kerr et al. 2018) and one systematic review (Coyne et al. 2018). The remaining six articles comprised of two service evaluations (Gravelle et al. 2015, Bowmer et al. 2008), two commentaries (West and Mogazel 2016, MacLusky and Keilty 2018), one panel of experts review (Lanzkron et al. 2018) and one relating to the use of the *Ready Steady Go Programme* (Connett and Nagra 2018). In contrast to previous literature searches, on this occasion literature from the UK / Ireland (8) outweighed the literature from the USA / Canada (6), which could be reflective of an increasing interest in the area of adolescent health and more specifically the transition of young people to adult healthcare services.

Despite the publication of the NICE guidelines *Transition from Children's to Adult's Services for Young People Using Health or Social Care* (2016), this, as indicated on the Web page, is only applicable to England. Due to the devolved nature of health within Wales, there is usually a lapse between any UK publication and the adaptation of such documents to a Welsh context. To date, no such updated information exists within Wales, other than local county council (for example Flintshire) publications, such as the *Parent and Carer Guide to Transition Process for Young People with Disabilities* (2017). However, this

relates to transition in its broadest sense and is viewed from a local authority healthcare provision perspective and does not fit within discussion pertaining to individuals with CF.

A number of authors (Gravelle et al. 2015, Sawicki et al. 2017, West and Mogazel 2016, Bowmer et al. 2018, Crawley et al. 2018, Kerr et al. 2018,) recognise the increasing longevity of young people within the CF community. Gravelle et al. (2015) identifies that in Canada, more than 50% of individuals with CF are adults and in the USA, Sawicki et al. (2017) suggests that the number of adult CF centres have expanded over a ten-year period. Conversely, although Lanzkron et al. (2018) acknowledge the increasing longevity in CF, they also recognise the clustering of deaths, which peaks when young people are in their twenties, caused by increasing lung damage and reduced lung function, validating CF as a life limiting condition.

Kerr et al. (2018) in their mixed methodology study, recognise that although transition has been on the “international healthcare agenda for over thirty years” (p126), improvements have not necessarily been made and young people are still not receiving the transition service or the support they need during the transition process. This is an important observation as CF management is complex and transition can compound this (Crowley et al. 2018). Particularly as there are stark differences between child and adult healthcare services (MacLusky and Keilty 2018) and young people will eventually need to take more responsibility for their own care (Lapp and Chase 2018).

With regard to pre-transition information, Bowmer et al. (2018) undertook a small study (N=37) whereby a questionnaire was used to seek the views of young people prior to their transition to adult services within one CF centre in England. The centre implemented the Ready Steady Go (Connett and Nagra 2018) checklist and one of the aims of this study was to evaluate the effectiveness of this process within their centre. Bowmer et al. (2018) identified that although the majority of participants (N=30) believed that they had been given enough information regarding CF itself, more than half (N=19) felt that they did not have enough knowledge regarding the transition process. This could have been why a third (N=12) of the participants had limited confidence regarding increasing their healthcare independence (Bowmer et al. 2018).

Therefore, young people (Crowley et al. 2018) as well as parents (Fixter et al. 2017) need support to help facilitate a successful transition to adult services. This is particularly relevant as stress can have an adverse effect on parents (Fixter et al. 2017), leading to parental resistance (Bourke and Houghton 2018), which could inhibit the transition process. It is important therefore that parents (as well as young people) receive clear information from “a trusted and supportive source” (Coyne et al. 2018 p652). Staff within children’s services are ideally placed to provide this information, which should emphasise the differences between child and adult services (Coyne et al. 2018), so that parents know what to expect (Aldiss et al. 2015) following transition. This will enable them to better support their young person throughout the transition process, as it is not only young people, but also the parents who are undergoing the transition experience.

2.9 Chapter Summary

This chapter has critically reviewed the literature related to CF and Transition. As anticipated, the majority of this literature was from overseas (predominantly the USA) although some UK studies were reviewed. Despite the considerable amount of available literature on the topic of transition the studies that specifically related to CF and transition were limited. The majority of literature had more of a generic transition focus whereby participants with a range of medical conditions were included in the studies. The key messages from this chapter are;

- There is limited research related specifically to transition and CF in the UK and none to date within Wales.
- The increasing longevity of young people with CF necessitates the development of planned co-ordinated and evaluated transition programmes that occur with the input of young people and parents.
- Transition continues to be a stressful process for adolescents and parents and can still be a haphazard process.
- A number of barriers to the provision of transitional care are recognised and include lack of adequate preparation, the challenge of changing caregivers, a lack of involvement in the decision making process and a lack of information sharing.

- Changes in care delivery (reduction in care) and issues surrounding infection control were also of concern to young people with CF and parents.
- In relation to service provision, adolescent healthcare services in the UK are limited in comparison to countries such as the USA and Australia and the lack of specific adolescent health education for UK physicians, nurses (and other healthcare providers) reflects this.
- To improve overall standards of care for young people in general and in particular those with CF, this needs to change.
- Transitional care should provide a smooth interface between child and adult services and an ineffective transition experience has the potential to have a lasting impact on the adolescent and their parents, including adverse health outcomes.

In the following chapter, the theoretical and methodological considerations relating to this study will be discussed.

Chapter Three

Theoretical and Methodological Considerations

3.0: Introduction

This chapter will discuss the theoretical and methodological considerations that have led to the structuring of this research. To add clarity to the discussion, terms and definitions will be identified, and the way in which the theory underpinning this research is integrated with practical application, will be outlined.

3.1: Values and Guiding Principles

Apart from the guiding principles that led me to start this research and have maintained my determination to complete it, I did not start with any specific philosophical underpinning in mind. This came with reading around the topic itself and from discussion with my reviewers at an early progress meeting when I was asked about a theoretical framework. As a consequence, because this study originally set out to examine the experience of adolescents, in the early stages, some thought was given to using an adolescent theoretical model to structure this study, although after due consideration this was rejected.

During my reflection around using an appropriate framework I kept returning to four basic facts:-

- children's services and adult services are different
- adolescents become used to the way practices and procedures are undertaken within children's services
- when they transition, adolescents need to learn about the way practices and procedures are undertaken within adult services
- to do this they need to adapt to, and accept the changes and differences between child and adult services

Further reading led me to consider a theoretical framework that was not specifically associated with adolescence, but related more to the adaptation of individuals to different situations.

3.2: The Roy Adaptation Model

Initially due to recognition of the need to adapt from child to adult service, the Roy Adaptation Model (RAM) (Roy 2009) was thought to be an appropriate framework for this thesis. This model identifies four main adaptive modes; Adaptation, Person, Environment and Health, in addition to the Goals of Nursing. At the time it was felt that the model fitted within the concept of transition as this physical move from child to adult services for young people with CF, can be described as an adaptive process. Additionally, when parents were included as participants, the choice of RAM appeared to be advantageous because if a theoretical framework specific to adolescence had been used, it would not have been as easy to include parents in the study. Furthermore, RAM appeared to fit well with Interpretive Phenomenological Analysis (IPA) which has been used within this study and will be discussed later in this chapter. Therefore at the time, the decision to use RAM appeared to be rational as it appeared to be a suitable match to several aspects of the study.

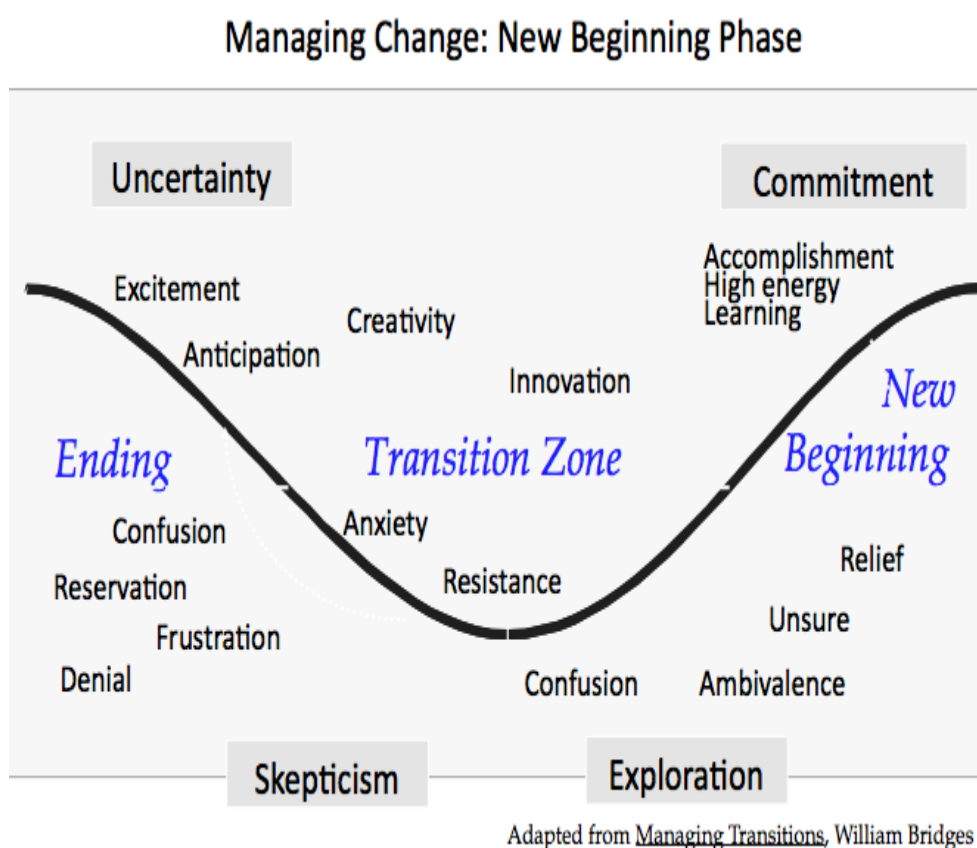
However, RAM is a complex framework and on reflection, it was not easy to provide a convincing argument that there was congruence between the transition process and RAM. Despite working with RAM for some time, it became increasingly evident that it was not fit for purpose and the decision to use it as a framework for this thesis needed to be reconsidered. Therefore it was 'back to the drawing board' to enable me to find something that fitted better with the study and provided a more appropriate theoretical framework.

3.3: Further Considerations

Following a period of reflection I began to consider that although young people and their parents *need* to adapt to change, this is not a process that we as healthcare providers can *force* on them by using a framework such as RAM. One cannot *make* someone adapt and accept change, it is a process that young people and their parents need to come to in their own way, with some being more successful than others. This led me to consider that perhaps it is not actually the adaptation itself that is important, but the way in which individuals reach that level of acceptance and change. Given that some young people 'do fall through the net' post transition, this also led me to question what is actually done to facilitate the process of acceptance and change in individuals who are unable reach this themselves. Therefore, following further exploration and reading, I decided to consider using the Bridges Model of Transition.

The Bridges Model of Transition (Bridges 2009) was first developed in 1995 as a method of managing groups and or individuals predominantly within business, to make and accept change. However, the Bridges Model of Transition is a simplistic model and its flexibility enables it to be applied to a range of different situations including transition within a healthcare setting. It has also been used in previous research related to adolescent transition (Dima and Skehill 2011). Within this model, where the acceptance of change may be problematic, ways of *facilitating* change are suggested. The Bridges Model is often depicted in diagram form and there are numerous adaptations of this available, including the one depicted below.

Figure 2: The Bridges Model of Transition



Although there are several depictions of the Bridges Model of Transition, I particularly like this one identified in Figure One as to me it represents a 'roller coaster' ride and this resonates with me for two reasons. Firstly because during one of the interviews a mother had described her experience of living with CF as a being like a roller coaster of ups and downs. Secondly, when I was asked to

present at a postgraduate student symposium, the title of my presentation was Roller Coasters and Tunnels: The Challenges of Data Collection and Sampling. Therefore, the diagram of the Bridges Model depicted in this research is appropriate to both the transition experience and my own experience of undertaking this research. Additionally, despite its developmental focus on change management, the Bridges Transition Model also fits well with the principles of IPA, and later in this chapter, this will be identified in more detail.

3.4: The Bridges Model of Transition (BMT)

BMT recognises that to make any form of transition, change needs to occur however, BMT also recognises that there is a considerable difference between transition and change, with change being the simpler of the two. Bridges (2009 p3) describes change as being “situational” and relates this to an external change, something that is almost out of the control of the individual, such as actually needing to move to a different location. This makes BMT relevant to this current study as the participants who transitioned from child to adult services all needed to move from one hospital location to another.

Conversely, Bridges views transition as being a more complex psychological three stage process that individuals need to work through to be able to accept the changes that the transition brings. Although Bridges (2009) recognises there are differences between change and transition, to be effective, they are both reliant on each other, and if all the transition phases are not worked through effectively, change is not accepted and does not fully occur. Although it has been established that Havighurst’s Tasks of Adolescence would not be used due to the dated nature of Havighurst’s theories, it does have a similarity in keeping with BMT in that the individual needs to work through transition (or the tasks) at a subconscious level. In relation to relating BMT to adolescence, the three phase trinity of transition within BMT also equates to the three phases of adolescent development; early, middle and late, therefore, BMT is also applicable to the construct of adolescence as a whole.

Interestingly, the three phases of BMT are described as starting with an ending, before moving into the neutral zone and then the new beginning (Bridges 2009). Although this initially gives the impression of being the ‘wrong way around’ as the perception is that all things should start at the beginning, in relation to transition, the process is actually logical. Individuals who are transitioning to adult services

are leaving child services and as a consequence, also leaving what they know and understand behind, thus *ending* that phase of their life. It is a time of loss and letting go and as identified within Chapters Five and Six of this study, adolescents and parents undergoing the transition to adult services can find letting go difficult. Bridges (2009) recognises that this is a difficult time for individuals making any form of transition and that it is also a time of loss that people need help in coming to terms with.

The neutral zone is the 'in between' time where changes have occurred, but they may not be completely functional. Within this study, that was evident as one of the participants (Molly) when first interviewed had effectively been transitioned in that she would no longer be admitted to children's services, but she had not yet been admitted to adult services. It is during the neutral zone that psychological readjustments have to be made, to enable acceptance of the 'new ways' to occur. It is easy to understand that when individuals are within the neutral zone, they can become ambivalent and disengage with the 'system'. In relation to transition, and 'falling through the net' this is identified in section 2.6 of this thesis.

If the process is managed effectively, the final phase is the new beginning. Bridges (2009 p5) suggests that this is when the individual develops a "new identity" as well as embracing new experiences, finding renewed energy and as a consequence the new change starts to work effectively. In the context of transition from child to adult services, the new beginning relates to the young person being able to manoeuvre the new healthcare system and being able to manage their own care effectively. Viewed this way, the 'new identity' becomes that of a self-managing adult patient within adult healthcare services. Within this process, parents also need to achieve a new identity in that they now need to play more of a supportive role as opposed to a full time care giver for their young person and a full time manager of their condition (CF).

Therefore, as this current study seeks to determine the experiences of young people and parents, in relation to the transition from child to adult services, it became apparent that BMT would be a more suitable framework to use, as opposed to either of the three previously identified theoretical frameworks. Additionally, BMT can be applied to adolescence as well as the transition process and as it focuses on the individual and the external changes that fit within the life world of the individual, it fits with the humanistic nature of IPA, which will be

discussed later in this chapter. An attempt to clarify these correlations, has been outlined in the tables below.

Table 4: Bridges Model of Transition

1: Bridges Model of Transition (BMT)		
Ending	Neutral Zone	New Beginning
Letting go of old reality	No man's land, the in-between stage chaos / confusion can become 'stuck' in neutral zone – may need supporting through it	New attitudes and understanding
2: BMT Applied to Adolescence		
Early (11-14) Ending	Middle (14-17) Neutral Zone	Late (17-20/25) New Beginning
Pre- puberty Ending childhood In lower age group – start of physiological change	Puberty Major physiological change plus psychosocial change	Post puberty Majority of change complete – capable of reproduction (but this can be earlier)
3: BMT Applied to Basic Transition Process		
Pre transition Ending	Process Neutral Zone	After Transition New Beginning
Preparation	How its conducted	Accepting new situations
4: BMT Applied to Transition Process During Adolescence		
Early Adolescence & Ending	Middle Adolescence & Neutral Zone	Late Adolescence & New Beginnings
Transition highlighted and some pre transition preparation provided	Transition Preparation increases and date of transition should be set	Essentially 'adulthood' (18yrs) Transition may / should have occurred by this time

In the table above, the versatility of the model is demonstrated. In the first section, the model itself is presented and identifies the main components of BMT, ending, neutral zone and new beginnings. The second section, identifies how BMT can be applied to adolescent development with the 'ending' signifying early adolescence and the ending of childhood. The 'neutral zone' equates to middle adolescence and the considerable psychological / psychosocial change that

occurs when young people are in a 'no man's land' trying to find their way from childhood to adulthood. Finally, the 'new beginning' can be related to late adolescence whereby the final changeover to 'adult' is complete physically, physiologically and psychosocially. In section three, BMT is applied to the basic construct of transition with the 'ending' representing the information young people and parents need regarding adult services. In this context, the neutral zone is the time when young people and their parents are coming to terms with the pending transition and the time until physical transition actually occurs. The 'new beginning' occurs when transition has been completed and young people and their parents have come to terms with the changes between child and adult services. Section four takes this a step further and links BMT to transition and adolescence, in relation to where the different steps within the transition process can or should be correlated to adolescent development and age appropriate timelines.

However, reducing the transition process to the three phases of BMT, is oversimplifying it, as there is more involved with each individual phase than just regarding it as 'before during and after' transition. In the following table, the issues that are applicable to each stage of the transition process for young people and their families have been outlined.

Table 5: BMT Applied to the Transition from Child to Adult Services

Ending	Neutral zone	New Beginning
Family Centred Care (FCC)	FCC maintained whilst in children's services	Patient Focused Care
Information	Hand over	Fact finding
Preparing to leave children's services	First admission	Working towards accepting changes
Leaving familiar staff – saying goodbye	Meeting new staff	Getting to know new staff and being know by new staff
Leaving familiar surroundings / procedures	Exploring new surroundings	Becoming familiar with new surroundings / procedures
Anxiety	Unsettled period – can become frightened and confused – could potentially lead to disengagement with services (support needed)	Lessened anxiety +/- potentially developing new anxieties (e.g. cross infection)
		If not accepting of change – 'fall through net'

BMT recognises that for many people change and transition will be difficult, but Bridges (2009) does not advocate a forceful method of compelling people to do this, as is the case with some businesses or companies. Instead, Bridges suggests that it takes time and offers solutions to *facilitate* change and ease the transition to prevent individuals as he puts it, “being hurt rather than helped” (Bridges 2009 p10). This suggests that Bridges is not just concerned with ‘getting the job done’ but that within the BMT there is consideration for the individual and the way in which, change and transition affects them. Offering ways to reduce anxiety and the effects of change and transition on the individual also suggests that BMT has a humanistic component, which sits well within the principles of this study.

3.5: Phenomenology

Edmund Husserl (1859-1938) is credited with developing phenomenology as a specific research concept early in the 20th century. However, the basics of phenomenology are grounded in the ideas of a number of 18th century philosophers. Husserl, described phenomenology as a means of collecting *describing* and analysing information regarding the everyday “lifeworld” or lived experiences of participants (Todres and Holloway 2006 p225). Husserl recognised that in trying to understand the ‘experience’ of others, it was possible that the preconceived ideas of the researcher could try to make things ‘fit’ where they did not (Smith et al. 2009). Therefore, in descriptive phenomenology, researchers approach their study by trying to remove any preconceived ideas they may have regarding the research topic, which is described by Husserl as ‘bracketing’.

Heidegger (1889-1976) took Husserl’s concept of phenomenology a step further and developed ‘hermeneutics’, or hermeneutic phenomenology. Heidegger recognised the importance of *understanding* and making meaning of the lived experiences of individuals, as opposed to trying to analyse their experiences based on a description alone. Therefore, hermeneutics seeks to understand the human perspective within the research. The researcher does not bracket their own experience and any preconceptions related to the research are used to add meaning to the findings and help to identify new concepts, similarities and differences within the research (Moule and Goodman 2009). Hermeneutic phenomenology generally takes the form of narrative, which is then analysed to

enable the researcher to develop a deeper *understanding of what life is like* for the participant (Flick 2009).

Therefore, the work of Husserl and Heidegger are similar but different. Both are leading figures in the development and advancement of phenomenology and one can be seen to build on the work of the other. However, whereas Husserl concentrated on the descriptive aspects of phenomenology, Heidegger focused more on the interpretation and meaning of the lived experience of the individual (Smith et al. 2009).

In relation to this study, given that I have experience in adolescent health and have worked in areas where transition programmes are in place, I did not feel that Husserl's phenomenological approach would work well for me. I do not believe that it is possible to *completely* bracket one's thoughts and ideas, or one's knowledge and experience of a particular topic. Additionally, I wanted to determine what the *experience of transition was like* for the participants, how they felt about it, what meaning it had for them and *how it had been experienced*. Consequently, I decided not to use this approach.

Heidegger's phenomenological approach was initially more appealing for me as the hermeneutic aspect of trying to *understand* the participant's perspective within the research. Heidegger does not expect the researcher to bracket their own experiences, as any prior knowledge is used to bring additional meaning to the findings. The approach of non-bracketing was easier for me to align my own thoughts with. I also feel that when I undertook the interviews, the fact that I had pre-existing empirical and experiential knowledge related to CF and adolescence made it easier for people to talk to me as they knew that to a certain extent I *understood*, and that lengthy explanations regarding CF were not needed. Additionally, the hermeneutic aspect of Heidegger's work, would enable me to develop an understanding of the participant experience. However, this led me to question, whether or not *my interpretation and understanding* of what the participants thought of their transition experience was actually that important. The most important part of this study are the participants, it is their stories that are being told and therefore it should be their interpretation of their experience and not mine that I should be trying to understand and record.

The humanistic nature of this study, and the qualitative phenomenological approaches that were explored during the early stages of this study, led me to investigate the use of Interpretive Phenomenological Analysis (IPA) in conjunction with the BMT. The aspect of IPA that most interested me was the double hermeneutic (Smith et al. 2009).

IPA is one of the more recently developed approaches to qualitative research, it has three main theoretical components; phenomenology, hermeneutics and idiographic. The development of IPA has clearly been influenced by some of the leading philosophers including Husserl and Heidegger, in that it focuses on the experience and interpretation of life events. However, IPA aims to take this a step further by trying to make meaning of the interpretations (Smith et al. 2009).

3.6: Interpretive Phenomenological Analysis (IPA)

IPA was originally developed for use within psychology (Brocki and Wearden 2004), but has rapidly moved into other disciplines such as social sciences and healthcare (Smith et al. 2009). The premise of IPA is that by following due process, the researcher seeks to interpret the participant's interpretation of the subject being studied (the participants' own individual life stories) by means of a double hermeneutic, so that it is the participants' subjective views that are being related (Smith et al. 1999). The philosophical background to IPA has three main components; phenomenology, hermeneutics and idiographic.

3.6.1: Phenomenology

The philosophical background to IPA was discussed in part, earlier in this chapter where the similarities and differences regarding the work of Husserl and Heidegger were noted. IPA has its basis in both descriptive and interpretive phenomenology and has clearly been influenced by some of the leading phenomenological philosophers such as Husserl, Heidegger, Merleau-Ponty and Sartre. All of these individuals are considered to be leading figures in the development and advancement of phenomenology and whereas some of their work appears to diverge, starting with Husserl, they all build on, and complement the work of each other. However, whereas Husserl concentrated on the descriptive aspects of phenomenology, Heidegger, focused more on the interpretation and meaning of the lived experience of the individual. Merleau-Ponty, blends the work of Husserl and Heidegger together. However, Merleau-Ponty diverged in particular, from Heidegger's viewpoint regarding the

worldliness of man's existence as being more related to being embodied in the world, and as such this shapes our individual outlook on life. Again, following on from the work of Husserl and Heidegger, Sartre focuses on the 'being' and the development of self, placing importance on the development of the individual and who they become (Smith et al. 2009).

Each of these philosophers have contributed to the development of IPA in their own way. Husserl's early work demonstrated the importance of capturing and describing the individual experience. Expanding on Husserl's work, Heidegger, Merleau-Ponty and Sartre attempt to place this in a wider context, thereby focusing more on the lived experience of the individual. Consequently, it is the interpretation of the lived experience that becomes more important. It is this that forms the basis for IPA by way of the 'double hermeneutic'.

3.6.2: Hermeneutics

Hermeneutics is the theory of interpretation (Smith et al. 2009). Although hermeneutics was incorporated into Heidegger's work, it was not of his own invention. Hermeneutics has its foundations in antiquity and the interpretation of biblical and other religious texts, as the belief is that understanding can only be achieved by the individual's interpretation of a situation (Debesay et al. 2008). Other philosophers such as Gadamer were also interested in hermeneutics although he was most interested in interpretation from an historical context, thereby attempting to learn from the past (Smith et al. 2009).

One aspect that all hermeneutic philosophers have in common is the hermeneutic cycle, whereby the researcher seeks to interpret the *participant's interpretation* of the subject being studied by means of a double hermeneutic, so that it is the *participant's* views that are being related (Smith et al. 1999). The principle of the hermeneutic cycle is that to understand the whole, one must first understand the part and to understand the part, the whole needs to be understood. On face value, this sounds illogical, a little like the old chicken and the egg riddle. However, it is logical, if the whole is disassembled into parts, and then reassembled back into the whole, this enables each section to be analysed and placed back into context. Smith et al. (2009) use the analogy of words and sentences to explain this concept, and this is actually a very good way of approaching it. In the English language several words look and / or sound the same, but would have very different meanings when placed within the context of

a sentence. Therefore, by removing the word (the part) from a sentence (the whole), it can render both the word and the sentence as meaningless. However, analysing the words individually and then returning them to the whole (the sentence), would give an added meaning and deeper understanding to the sentence when the words are read in context (Smith et al. 2009). The same principle used on a wider scale, would give added meaning to the analysis of research data and the investigation of the research problem as a whole, again by the use of the double hermeneutic.

3.6.3 The Double Hermeneutic

Giddens developed the term double hermeneutic (Kim 2004) to describe how natural sciences are 'single' hermeneutic disciplines, in that scientists must develop shared systems of thought about the appropriate way to describe the natural phenomena in question; a one way street. In other words, scientists can generally be safe in their assumptions that how people *feel and talk* about phenomena will do little to change them. They are what they are and scientists generally do not need to concern themselves with the question of *what* their knowledge justifies. In contrast social scientists believe that some human behavioural phenomenon are digested by human actors with genuine causal consequences, or in other words an attempt is made to develop an understanding of what the individual experiences. Therefore, the human sciences differ from the natural sciences in that they confront a 'double' hermeneutic or what could be termed a two way street.

3.6.4: Idiographic

The third component of IPA is idiographic analysis. Originally, in relation to research, idiographic analysis in its broadest self, distinguished between studying specifics or generalisations (nomothetics). However, in psychology, idiographic analysis relates to the study of individual people as opposed to groups (Larkin et al. 2006).

In IPA, idiographic analysis pays attention to the 'particular'. Smith et al. (2009) describe this as being on two levels; firstly in relation to the detail and depth of analysis, which is specific to IPA. Secondly, the idiographic component of IPA relates to the researcher's understanding, of the way in which, a particular event has been understood from the perspective of the person or people experiencing it. This approach has often been described as the "insider perspective" (Larkin et

al. 2006, p102) and relates back to the concept of the double hermeneutic. On that basis, idiographic analysis can be used with single participants, or a small number of participants.

In IPA however, the use of idiographic analysis could be viewed as being contradictory as although the emphasis is focused on the particular, it does not necessarily follow that this focus is on the individual person. Although the experience being studied is unique to the individual, from a phenomenological perspective, the individual is also influenced by their lifeworld experiences and this as such, could alter their perception of the situation being studied. However, Smith et al. (2009) identify that despite this, the individual participant can still provide the researcher with an exclusive insight into their own experiences.

To enable a focused approach in relation to the individual's particular experience, the analysis of data used in the IPA methodology follows a systematic and structured approach. Initially, interview transcripts are analysed in a detailed and intensive manner, and this is undertaken on a systematic case by case basis. Once this has occurred, and where there is more than one participant, the transcripts can be compared to determine any similarities and differences. Verbatim participant quotes are then used to construct a narrative of the participants experiences (Smith et al 2009). The actual process involved in using IPA within this current study will be outlined in chapter four.

3.7: Theoretical and Methodological Fit

IPA and the BMT are compatible as they are both have a basis in humanistic principles. One of the main aspects of IPA is that it focuses on life experiences and the interpretation of those experiences. BMT also focuses on the individual and the way in which they respond to change and the process of transition, which enables change. Therefore, BMT and IPA dovetail together, and using both of these concepts to determine the experiences of young people with CF and parents in relation to the transition process, would be appropriate. Additionally, BMT is a flexible framework that has been used in the past with other qualitative research studies that have a basis in phenomenology. Therefore, BMT and IPA fit together as they both include aspects of humanism, phenomenology and are concerned with the experiences of the individual.

As BMT has the potential to focus on individuals as well as groups, this could be considered to be a humanistic model and as such would sit well within IPA, which focuses on the life experiences of the individual and the interpretation of those experiences. On reflection it is now clear in my mind that the initial choice of using RAM as a theoretical framework within this study was incorrect. RAM was complex and did not really lend itself to the exploration of the individual experiences of the participants and as a consequence did not enable the same theoretical and methodological fit as BMT and IPA.

However, because the theoretical framework for this study was changed this altered the focus to a certain extent from adapting (RAM) to facilitating change (BMT). Therefore, the decision was made to revisit all of the participant transcripts and reanalyse the data. This enabled me to review the data with 'fresh eyes' and a renewed focus based on the use of the BMT as the theoretical framework.

3.8: Chapter Summary

The recognition that improvement needs to be made within the current level of healthcare provided to young people with chronic illnesses such as CF in the UK, has been a guiding principle of this research. The main points of this chapter were to identify:

- the values and guiding principles of this research study.
- the philosophical alignment, and potential theoretical frameworks prior to demonstrating why the chosen theoretical framework was selected.
- BMT as the theoretical framework used within this research and the theoretical and methodological fit between BMT and IPA.

The following chapter will provide an overview of the research design used to undertake this study.

Chapter Four

Research Design

4.0: Introduction

An overview of IPA has already been provided in the previous chapter. Therefore, this chapter will focus on the research design used within this study. The research process will be outlined and discussed. The sample will be identified and the difficulties experienced in the recruitment of participants will be highlighted. Data collection and the analysis of the data will be discussed in detail and various ethical considerations pertaining to researching with young people will also be discussed.

4.1: Research Procedure

This section will outline the sample used within this study and briefly introduce the participant group. Details of the difficulties encountered surrounding recruitment will be identified, and the method of data collection will be outlined. Finally, in this section, the procedure for undertaking the data analysis will be identified.

4.1.1: Sample

The initial intention of this study was to recruit young people with CF, who had made the transition from child to adult services in Wales, aged between 18 - 24 years at the time of interview. However, this changed following a conversation with a parent after I had interviewed her daughter, which led me to reconsider only recruiting young people. The mother identified how difficult she herself had found the transition process and she was clearly anxious to talk about her own experience. This led to a 'light bulb' moment when I realised that I had missed out on an opportunity to have a different perspective on this study and that by including parents, I would also be providing them with the opportunity to have their voices heard. Therefore, a total of eight participants were recruited to this research study, they were divided into two groups, four young people and four parents. In order to maintain anonymity, (NMC 2015) all participants are identified by a pseudonym.

There are two main CF centres in Wales, one for children and one for adults, both of which are based in the Cardiff area (UK Cystic Fibrosis Registry 2015). However, some children / adolescents with CF are cared for in regional district

general hospitals (DGH) in partnership with the staff at the CF regional centres. This reduces the need for frequent visits to Cardiff, but only occurs until the time of transition, at which point all CF management is provided through the adult CF centre. In this study, two of the young people participants had transitioned from child to adult services in Cardiff, whilst the other two had transitioned from children's services in two different DGHs to the adult service in Cardiff.

The number of adolescents who transition annually to adult services is variable but averages at four each year. Therefore, when this study commenced it was anticipated that approximately 12 young people would be recruited to the study. However, recruitment was problematic from the outset and the anticipated number of participants was not reached. Furthermore, the time lapse between transition and interview varied, with 15 years being the longest and one year being the shortest. One participant was in the process of making the transition during the time of her interview and as a consequence, she agreed to be interviewed for a second time following her first encounter with adult services. This is the only situation where two interviews were conducted with the same participant.

Due to difficulties with recruitment, which will be discussed in more detail later in this chapter, the oldest of the younger participants recruited to this study was 33 years of age. Additionally, one young man, although initially agreeing to participate and returning a consent form, withdrew his consent. As a result, within the first group, four young people; three females and one male, participated in the study.

Following the recruitment of parents into this study, four parents, (three mothers and one father) were also interviewed. However, not all the young people and the parents 'matched' as family units. The relationships between the parents and the young people where appropriate, are outlined in Table 6.

Table 6: Participant Relationships

Participant	Grouping	Comment
Karen	Young Person (28 yrs)	Mother declined interview
Ben	Young Person (19 yrs)	Mother declined interview
Molly (interviewed twice)	Young Person (18 yrs)	Daughter to Carol

Katie	Young Person (33 yrs)	Daughter to Sally and Jeff
Jenny	Parent (single)	Mother of Tom (Tom himself withdrew consent)
Sally	Parent (married)	Mother of Katie / Wife of Jeff
Jeff	Parent (married)	Father of Katie / Husband to Sally
Carol	Parent (single)	Mother of Molly

4.1.2: Recruitment

Recruitment to this study was a lengthy process that spanned a period of approximately three and a half years. Overall, recruitment is best described as being in three phases, with Phase One, via the CF Trust Website and by using snowballing to recruit to Phases Two and Three. A contact employed at the CF Trust was also involved in the snowballing process by inviting other individuals who had CF to participate in the study. Each of the three phases will now be outlined in more detail.

Phase one of the recruitment process commenced by gaining ethical approval to recruit participants via the CF Trust Web page (Appendix 3). The rationale for this was that young people tend to engage well with social media and since the exposure to cross infection was recognised, social activities and groups within the CF community have been curtailed. Consequently, the CF Trust have developed a number of 'forums' on their website to enable children, young people and parents to communicate with each other. The forums are well subscribed to, and are on a national and regional level.

Contact was made with the CF Trust to gain permission to recruit via their webpage and I was advised to liaise with the Public Affairs Officer (PAO) for this area. Currently, the CF Trust has three PAOs, who are located in England, Scotland / Isle of Man and Wales. The Wales PAO proved to be most helpful in facilitating permission to use the CF Trust website, providing additional information on CF resources and further contacts within the CF Trust. At the time I was advised that the CF web page was well subscribed to, although it became evident that the CF Trust do not track or keep statistics on the number of people who actually use the site.

Once permission had been granted by the CF Trust to make postings on the Welsh CF Trust Forum pages, a participant information sheet (Appendix 4) and a consent form (Appendix 5) for young people were developed and this phase of recruitment commenced in September 2011. The CF Trust has individual forum pages for children, adolescents and parents. The same message was posted to both the adolescent and the parental forum with the reasoning that this would potentially widen the reach of the request. The proposed message was discussed with my supervisor as well as the Wales PAO and it was determined that it should be brief and succinct. Therefore, the message was simple and to the point and is outlined in Appendix 6.

However, given that permission to use the CF website had been granted, I was surprised to receive an email from someone at the CF Trust trying to determine my motives for undertaking this research. The matter was resolved speedily and satisfactorily by the Wales PAO, but during this time all the 'postings' to the CF website had been removed effectively halting recruitment to the study. This appeared to have had a lasting effect on the recruitment process, as between September 2011 and January 2012 only one person was recruited, and as the CF Trust do not track the number of people who use the site, I was unable to determine how many people had actually viewed, but not responded to, the requests for participants. Despite leaving the posts in place for some time after this incident, it became evident that recruitment via this method was not going to improve and that an alternative form of recruitment needed to be pursued.

A range of options regarding recruiting participants were considered including the possibility of recruiting CF expert patients. However, as the CF expert patients are limited in each region, this would have meant taking the research outside Wales, which moved away from the focus of my original research. On this point, the original intention was not to limit the focus of the research to a parochial picture, but because there had been no research undertaken specifically relating to CF and transition in Wales. Therefore, taking the research out of Wales, would not have provided it with the unique aspect I had anticipated.

Recruitment via the adult CF centre was also considered and prior to making an application to the NHS R&D committee the feasibility of this was investigated. Contact was made in February 2012 with the lead CF physician and two meetings took place with the CF multidisciplinary team (MDT) over a period of six

months. However, it was unfortunate that the lead CF physician was unable to attend either meeting. A request was made for assistance in recruiting participants via the CF clinic, and although it was agreed that the request was feasible, this did not come to fruition.

Phase two recruitment commenced following permission from the South East Wales Ethics Committee to change the recruitment strategy from using the CF webpage to snowballing (Flick 2014). This started in January 2014 with the PAO at the CF Trust, as well as colleagues, facilitating this process. One further participant was recruited via the CF Trust, whilst two other participants were recruited via existing participants and colleagues. Snowball recruitment is an accepted way of attracting participants to a study where the population may be hard to reach (Penrod et al. 2003) or where the researcher has limited access to a sample, which was certainly the case for this study. In this study the snowballing method was also used to connect with parents.

Phase three of the recruitment process developed from the first two interviews with young people, as it became evident that an opportunity had been lost within this study. In the early stages of the study, including parents as participants had been given some consideration. Indeed, parental responses to transition have already been researched, and some of this work had been included in the literature review for this study. However, parents were not included at the start of this study for two main reasons. Firstly the focus of this study was on the adolescent experience, and secondly, very naively, I anticipated that I would have more than enough data from interviewing young people

During their interviews, two of the younger participants identified that their mothers had experienced a particularly difficult time during the transition process. Additionally, as previously mentioned during a conversation with a mother following a participant interview, she identified the difficulties she herself had experienced during her daughter's transition. This reaffirmed that transition was not only about the individual but also involved the main carer and it was decided that including parents in this study was important. Again, advice was sought from the South East Wales Ethics Committee with regard to including parents in the study and permission was granted (Appendix 7) and over a very short period of time, four parents were recruited to the study. In keeping with the requirements of the ethics

committee, an information sheet (Appendix 8) and consent form (Appendix 9) were both developed for the parental participants.

4.1.3: Data Collection

Communicating with and engaging adolescents in research can be difficult (Spence and Devanny 2013). Consequently, it is common to use focus groups in adolescent research (Bassett et al. 2008) as being interviewed in a group setting helps to prevent young people from feeling pressured (Peterson-Sweeney 2005). This is a reasonable comment, as a focus group setting may make the adolescent feel more relaxed and therefore more inclined to talk. However, focus groups are not always appropriate (McDonagh and Bateman 2012) and this was the case within this research study.

Although focus groups are an accepted form of data collection within qualitative research, and can be used in IPA (Smith et al. 2009) the decision to use face to face interviews within this study was more related to an ethical issue as opposed to a methodological one as it relates to doing no harm. It has already been established within this thesis under section 1.5.1 Prevalence and Aetiology, that the lungs of the majority of individuals with CF are eventually colonised with a variety of pathogens, most commonly *Pseudomonas \aeruginosa* and *Burkholderia Cepacia*. Over time, this causes repeated lung infections, the main cause of morbidity and mortality so patients hospitalised with CF are managed in isolation (Badlan 2006) to prevent the risk of cross infection. Consequently, it would have been unethical to have considered using focus groups to gather data for this study. Although consideration was briefly given to the use of technology such as Skype, to facilitate a 'virtual' focus group, this was not pursued for two main reasons; firstly, my own limitations with this form of technology and secondly, because I felt that this may have inhibited discussion with the adolescent group. Therefore, participants in this study were recruited with the aim of undertaking individual in-depth face to face interviews.

During initial contact, the date, time and location of the interview were negotiated with each potential participant. The majority of the interviews for the young people and parental group were undertaken face to face. Ben's interview was the only one undertaken via telephone, as although he was happy to be interviewed,

he did not want to meet. To ensure privacy, I undertook this interview on my home telephone at a time when none of my family members were at home.

The remainder of the interviews were undertaken by negotiation with the individual participants. Two interviews (Jenny and Katie) were undertaken in pre-booked rooms on the university campus, whilst all other participants chose to be interviewed in their own homes. In the case of the married couple (Jeff and Sally) both interviews were undertaken on the same day to minimise disruption, but they were interviewed individually.

The length of the actual interviews varied and ranged between 45 minutes to 70 minutes. However, in keeping with the IPA process, sometime was taken prior to commencing the interviews to develop a rapport with the participants (Smith et al. 2009). During this time every effort was made to put the participants at ease and we discussed a variety of general issues. The only exception to this was Ben, who just wanted to get on with the interview, so in his case, the pre-interview 'chat' was reduced to a minimum.

All of the interviews (including the telephone interview), were audio recorded and additional written notes were taken during the interviews. As an overarching question, participants were invited to tell me about their experience of transition between child and adult services. Some additional questions were used as prompts and to maintain to focus of the interview. The additional / prompt questions (in easy to understand vocabulary) were:

- What did you expect before moving from child to adult care?
- Has your transition experience matched up to what you expected?
- Overall how do you think the transition experience worked for you?

Although I had prepared prompt questions, these were only used where necessary as any pre-interview agenda should be adaptable enough to suit the situation. In the main, and in accordance with the IPA process, I spoke to and prompted the participants as little as possible as the role of the researcher in IPA is as an "active listener" (Smith et al. 2009 p 64). This enabled the participants to speak freely and without interruption about what they felt was important to them. The prompt questions were only used to help me to focus the participants from wider issues to more specific ones and to help me to keep them 'on track' (Smith

et al. 2009). Despite the use of a schedule, it is recognised that sometimes the participant will move onto discuss a topic that is important to them, but does not necessarily follow the actual path one, would have expected them to take.

Smith et al. (1999) acknowledge that the interview process can be complicated by the researcher's own perceptions of the topic being researched but that these are necessary to enable the researcher to make sense of the participant's world. Therefore, throughout the interviews I was mindful that I should not be sharing my own experiences or expertise, be overly empathetic or try to provide opinions on the issues the participants were raising. Smith et al. (2009 p67) describe these as "interactional habits" and suggest that they should be replaced by "highly engaged listening and some well-timed and sensitive questioning" (P67). Therefore, at appropriate points throughout the interviews I was able to gently probe certain aspects of the discussion threads by actively listening and asking the participants questions such as 'do you want to tell me a bit more about that?' If the participants were in the middle of their narrative, or I noted a point that I felt was interesting and required further probing, I made a note of this and returned to it when the participant had finished speaking. This enabled relevant topics to be probed to a deeper level and is an interviewing strategy suggested by Smith et al. (2009 p65) as it sits well with "the inductive principles of phenomenological research".

Following the interviews, the audio recordings were transcribed verbatim as soon as practicable following the interview. This enabled my research schedule, prompt questions and interview techniques to be reviewed prior to the next interview (Smith et al. 2009). These issues were discussed with my supervisor, this enabled me to discuss the interview process, and to determine whether the questions I had asked had been appropriate in order to elicit the required responses and establish where improvements could be made prior to the next interview.

Individual participants were provided with a copy of the transcripts to review the content of their interview, with the aim of increasing the validity of the data (Flick 2014). All of the participants were offered the option of reading the interview transcripts following the interviews, although the majority of participants declined to do so. Only three participants (two parents and one young person) elected to review the transcripts and no post interview comments were provided.

4.1.4: Validating the Research

Gibson and Brown (2009) identify that proving validity in qualitative research can be a “thorny issue” (p59) and that the notion of trustworthiness is more appropriate. Trustworthiness is a term used within qualitative research to describe the credibility, dependability and transferability of the study itself and the results (Moule and Goodman 2009). In this study, credibility was achieved by accurately recording the verbatim quotes within the analysis and discussion chapters to ensure that the participant’s voice was heard. Dependability has been achieved by providing a step-by-step auditable trail in relation to the processes undertaken to complete this research, which includes the analysis of the research using the IPA process. Although this study has only been undertaken in Wales, it is quite likely that the findings of this study will not be unique to the geographical area it took place in.

However, within this study, it is possible to identify relevant aspects of validity. For example, procedural validity (Flick 2014) was accomplished by ensuring that with the exception of prompt questions, researcher discussion was kept to a minimum within the interviews, which enabled the participant’s voice to be heard. Respondent validation was also accomplished by offering and providing copies of the completed transcripts. Although, as identified earlier, this was not achieved with all of the participants.

4.2: Ethical Considerations

Due to difficulties with recruitment, ethical approval was sought and gained on two separate occasions from the South East Wales Ethics Committee (Appendix 1 / 7). Throughout the recruitment process, contact was maintained with the South East Wales Ethics Committee to seek advice and guidance on the process of changing recruitment strategies and the advice provided was invaluable.

The issue of choosing individual interviews as opposed to focus groups to collect data in order to prevent participant harm has already been discussed under section 4.1.3 Data Collection, and with the exception to this, there were no adverse ethical situations anticipated at the submission of the ethical application. Although the importance of adhering to strict ethical principles for all research participants is recognised, and the inclusion of parents in this study has been highlighted, the ethical discussion in this section will predominantly focus on

young people. The reason for this is that there are particular ethical implications that need to be considered when researching with young people.

Research participants with a chronic illness such as CF are potentially vulnerable and when researching with adolescents and young adults, there are also issues of power and control to be considered (Duncan 2010). Additionally, Heath et al. (2009) recognise that informed consent, anonymity and confidentiality are the three most important ethical issues when researching with young people.

Informed consent is an important factor with any research and this can be particularly challenging with adolescents (France 2004). As the participants had already made the transition from child to adult care, and had already reached 18 years of age, they were legally able to consent to participate in the study themselves. Participants in this study were provided with a clear written information sheet (Appendix 4/8) regarding the purpose and aims of the study to ensure that the nature of the research was understood, and written consent was obtained (Appendix 5 / 9).

Confidentiality is an important issue for young people (Bill and Knight 2007) and is particularly relevant within the research context. Within this study, confidentiality and privacy were maintained with individual participant responses and transcripts were coded to ensure anonymity, and participants were allocated a pseudonym. Although the PAO from the Wales CF Trust and some colleagues were involved in the snowballing process of recruitment, this only involved making contact with individuals with CF and providing them with my contact details. Interested individuals made direct contact with me and at no time were the PAO or colleagues used as intermediaries between the participants and myself. The matching of the participant pseudonyms and the actual names of the participants were only known to myself and if the need arose to discuss participants with my supervisor in relation to the analytical process only the participant pseudonyms were used. Additionally, as two of the participants transitioned from different DGHs and one of the two participants who transitioned from the same hospital managed her own intravenous therapy at home, it is unlikely that any of the participants came into contact with each other. Furthermore, with the exception of the married couple, all of the participants were interviewed on different days and in different locations thereby ensuring confidentiality and anonymity.

As identified in Table 6, in some cases more than one member of a family was interviewed and the interface between these situations were all managed differently. It was after Molly's second interview that a conversation with her mother Carol prompted me to seek ethical approval in order to include parents in the study. Therefore, Carol's interview occurred several weeks after Molly's. The interview took place in Carol's home and neither Molly nor her sister were present at the time, although Carol had informed Molly that she was also going to be included in the study.

Katie was the final participant interview conducted with the younger age group. At this time, ethical approval had been granted to include parents in the study. When the interview with Katie had been concluded and we were chatting socially, Katie suggested that her parents may be interested in participating in the study and she passed on my contact details to them. I was subsequently contacted by Jeff and to minimise disruption to the family, they decided to be interviewed on the same day. On the evening of the interviews both participants were interviewed separately with Jeff electing to be interviewed first.

In this study, all computer files were password protected and transcripts, notes and other data, including person identifiable data and the Dictaphone were kept in a locked filing cabinet in accordance with the requirements of the South East Wales Ethics Committee. Following completion of the study all data will be stored for 15 years by the sponsor (Cardiff University).

A reluctance to communicate can be an issue with some adolescents and poor levels of communication can be detrimental to the responses obtained during an interview. Therefore, it was important that young people were not coerced by family members to participate or that they agreed to be interviewed because they felt 'obliged' to do so. For this research study, reluctance to communicate was not an issue as the young people who took part in this study were a self-selected group of motivated individuals who had an interest in participating.

Based on the ethical principle of non-maleficence, participants undertaking research should not be subjected to harm in any way and participants who experience any harm or distress from being part of a study should be withdrawn (Duncan 2010). Therefore, the participant's right to withdraw from the study at any point was highlighted verbally, and was also identified on the written

information sheet (Appendix 4 / 8). It was also recognised that the participants may have wanted someone to support them during the interview or to be with them when information regarding the study was provided. However, this did not prove to be the case within this study.

Additionally, guided by the principle of non-maleficence, individual interviews, as opposed to focus groups, were used to collect data for this research. The reason for this has been outlined in more detail under section 4.1.3. Therefore, using individual interviews reduced the potential to cause any physical harm to participants involved in the study.

Maintaining the safety of young people is paramount. The researcher has a valid Disclosure Barring Service check (DBS), is registered with the Nursing and Midwifery Council (2015) as a children's nurse and holds a specialist qualification in adolescent health. It was anticipated, based on past experience that the majority of young people would choose to be interviewed in their own home. Therefore, in this instance the safety of the researcher also needs to be taken into consideration. To address this, when undertaking the interviews I always carried a mobile telephone and details of the researcher's location and mobile telephone number were left with my academic supervisor as per Cardiff University's Lone Worker Policy.

Although there were no anticipated ethical issues identified prior to the commencement of this study, two individual issues did occur in relation to a potential safeguarding issue and participant distress. Molly recounted a story from her admission to adult services, that was quite concerning and although she was 18 years old at the time, given that she was vulnerable due to her health status, it could have been considered to have been a safeguarding issue. The incident itself is outlined in detail in Chapter Five section 5.10. However, this situation had occurred several weeks prior to the interview and had been dealt with by both Molly and her mother Carol, who also highlighted the incident in her interview. After discussing this with my supervisor, it was determined that no further action needed to be taken.

The second incident occurred during Sally's interview, when she related the circumstances leading to Katie's diagnosis. Pietkiewicz and Smith (2014) suggest

that as the IPA interview can often raise emotive issues for the participant, it is important that the researcher observes and monitors the participant for signs of distress. During her interview I recognised that Sally had become distressed and tearful and it took a little while for her to compose herself. I suggested terminating the interview, but Sally was against this as she wanted to finish her story. As part of the initial ethical application, I had needed to make provision for situations of potential distress in participants. Therefore, I had already arranged for a colleague who was a psychologist and counsellor to provide her professional services to participants as required. This was approved by the South East Wales Ethical Committee and I had the psychologist / counsellor's contact details on hand during each interview. At the end of Sally's interview, I suggested that she may feel the need to talk to someone, but as she already had a counsellor, she declined my offer.

4.2.1: Negotiating Access

The fact that recruitment was problematic has already been noted and this point will not be laboured on any further. However, it is worth noting that although I was fortunate in gaining the support of the CF Trust PAO, she had CF herself, and there was a period during the undertaking of this study, where she was not in the best of health. Consequently, there were times when ethically, I had to limit my contact with her and encourage her to limit her involvement in helping to recruit participants to this study.

In relation to potentially recruiting via the CF clinic, I was advised that although the project was worthy, they did not have resources to help. Although I recognise that the NHS has considerable staffing issues, this was a little difficult to accept, given that the only requirement was for someone to place a label, on an already sealed envelope. Therefore, I did wonder whether the CF clinic staff were acting as unofficial 'gatekeepers', and as such, inadvertently impeded my access to young people with CF.

Bassett et al. (2008) identify the challenges of recruiting adolescents to research studies, particularly in situations where parents or others may act as 'gatekeepers'. Whilst it is accepted that gatekeepers work in the best interest of the young people they are protecting they are, nevertheless, in a strong position, with the power to give or deny access to young people in a range of settings (McFadyen and Rankin 2016). In some situations, 'gatekeepers' could be

considered to obstruct the young person's rights to give, or withhold their own consent to participate in research (Heath et al. 2009). I am not suggesting that this was the case in this current study and I do recognise the importance of protecting vulnerable individuals. However, I was unable to gain access to a considerable number of young people some of whom may have been interested in participating in the study, if they had been given the opportunity to do so. Conversely, the CF Trust PAO could also be viewed as a gatekeeper and she was a considerable help and enabled access to a number of individuals. Therefore, in this study, gatekeepers could be viewed as both facilitating and impeding the recruitment process (McFayden and Rankin 2016).

4.2.2: Over Researched Groups

In general, there is a lack of empirical and robust research data available in relation to adolescence and adolescent health (McDonagh and Bateman 2012). However, determining the views of adolescents is of primary importance to ensure that it is their needs that are being met. The knowledge gained from directly researching with adolescents can also serve to empower them as individuals (Powers and Tiffany 2006), increase the knowledge and understanding (Lewis 2004) of healthcare professionals and improve health outcomes (Peterson-Sweeney 2005).

Although research with adolescents is increasing, in a position paper prepared on behalf of the Society for Adolescent Medicine (SAM) identifying *Guidelines for Adolescent Health Research*, Santelli et al. (2003) recognise that adolescents are often not included in research due to ethical and legal considerations. Conversely, it has also been recognised that some groups of individuals within healthcare are over researched (Clark 2008). With increasing numbers of drug trials, physiotherapy studies and socially based research topics, it could be suggested that not only individuals with CF, but also their families also fall into the 'over researched' category.

Indeed, it was noted, that one of the participants (Molly), whose sister Anna is not affected by CF, had been recruited to a study being undertaken by a fellow student. This did not become apparent until I had completed Molly's interview and her mother (Carol) commented that Anna was going to be interviewed later in the week. Although in this instance, Molly had agreed to be interviewed by myself and Carol had consented to Anna being interviewed by my colleague, it did

necessitate the household being disrupted by two interviews being undertaken in the same week. Situations such as this have the potential to place considerable strain on the family and as a consequence, they may decide to disengage with any potential research project in the future (Clark 2008).

4.3: Data Analysis Using IPA

The aim of IPA is to specifically concentrate on analysing the way in which *participants* make sense of their experiences. It is this use of the double hermeneutic that makes IPA different to other forms of phenomenological approaches. Therefore, analysis in IPA focuses on the researcher "...trying to make sense of the participants making sense of x..." (Smith et al. 2009 p9), which in the case of this study is their experience of transition. To achieve this, a thorough analysis of the data, which moves from "the particular to the shared" and the "descriptive to the interpretive" (Smith et al. 2009 p79) is required. Therefore, the analysis of data used in the IPA methodology follows a systematic and somewhat prescriptive approach using a three level or funnelling method to 'drill down' to a deeper level of analysis. This includes 1) exploring ideographic and biographical information, 2) examining shared experiences to carry out a generalistic thematic analysis and undertaking 3) a more detailed analysis of significant events. Verbatim participant quotes are then used to construct a narrative of the participants' experiences (Smith et al. 2009).

Even though analysing IPA data is systematic, it is not necessarily a straightforward and linear process. Although it appears to be a sequential step by step process, IPA is convoluted and far less straightforward than originally anticipated. In part, this relates to my inexperience as a qualitative researcher, but the complex nature of IPA is also acknowledged by Smith et al. (2009). Therefore, Smith et al. provide a six step 'guide' to undertaking analysis in IPA, which is outlined as follows.

- Step 1 Reading and rereading
 - To immerse oneself in the data.
- Step 2 Initial noting
 - Examining semantic content and language at a descriptive, linguistic, conceptual level as well as deconstruction to

concentrate on the participant's words and their meaning in context.

- Step 3 Developing emergent themes
 - This is where the hermeneutic cycle comes into focus as the transcripts / sentences are disassembled to develop a greater understanding of the part to enable an increased understanding of the whole.
- Step 4 Searching for connections across emergent themes
 - Emergent themes are matched (abstraction) and clustered to form subordinate and superordinate themes. Superordinate themes can be formed from combining subordinate themes together.
 - Differing or opposing themes (polarisation) can also be identified at this point. Contextualisation of the narrative, the frequency (numeration) the participant identified a topic, and the function of the words used by the participant, are also analysed within step 4.
- Step 5 Moving to the next case
 - IPA can be used for single case studies so this section may not be required.
- Step 6 Looking for patterns across cases
 - Where more than one participant is used, themes can be compared and as part of this process, the importance assigned to each of them may be reassessed. (Smith et al. 2009 pp 79-101).

Although I initially contemplated using a software package (such as Nvivo) to analyse the data, after discussion with my supervisor I decided to forego this, in favour of working with hard copies of the data. As a novice qualitative researcher, I needed to come to terms with using the IPA process, which proved to be a considerable learning curve and as a consequence, I did not want to be in the position of negotiating an unfamiliar software package at the same time. I also believe that working exclusively with hard copies of the transcripts enabled me to remain closer to the data and the participant's stories.

4.4: Process of Analysis

Smith et al. (2009) suggest that there is no right or wrong way to undertake IPA, and they encourage researchers to be creative in their approach to IPA analysis. However, for this study I decided to 'stick to the plan' and follow due process. The

following section identifies the way IPA was applied to this study and the way in which the process was used to analyse the data.

4.4.1: Step One: First Encounter with the Text

Following each of the audio recorded interviews, in the first instance, the transcripts of the interviews were all hand written and only documented the researcher / participant dialogue. The recordings were then listened to again, to ensure that the details had been accurately transcribed and read repeatedly to enable me to become familiar with the content. Closely adhering to the IPA process this process was frequently undertaken in conjunction with listening to the audio recordings of the transcripts. This allowed me to make connections with and immerse myself in the data, so that eventually when I read the transcripts, I could 'hear' the participant's voice as I was reading and this enabled me to connect with them.

Smith et al. (1999) suggest that each of the individual transcripts should be set out on a three column grid formation, with the actual participant transcript situated in the middle column and the left and right hand columns used for collating notes, items of particular interest and similarities. However, in this study, the hand written notes were typed out into a five column table using a landscape page format. This enabled me to record who was speaking, as well as numbering the lines of the transcript to enable me to locate them accurately. An example of this is provided in Table 7, although, in reality, the notes columns were wider, thereby allowing more room for comments.

Based on this process, each of the interviews and transcripts are viewed as an individual process and, indeed, as IPA can also be used to present individual case studies each interview is treated as being unique. Therefore, in keeping with the IPA process regarding subsequent interviews, individual interviews do not influence each other (Smith et al. 2009, Pietkiewicz and Smith 2014).

Table 7: Brief Extract of Interview One

Notes	Line	Partic	Transcript	Notes
	7	Karen	Uhm, I was kept there for quite a lot longer than I probably should have been but it gave the CF team a bit of time to get me used to the idea that I was going to transition over to the adult team.	

4.4.2 : Step Two: Identifying Preliminary Themes

Starting with the first interview transcript, (Karen) initial notes were made on the printed transcript, which included identifying descriptive, linguistic, conceptual comments. Smith et al. (2009) suggest that this can be achieved by underlining areas of the transcript. However, as I use different coloured pens in my professional diary to differentiate between various task, meetings, teaching and other commitments, I found that using different coloured pens was useful when I worked with the transcripts to denote different levels of analysis. Therefore, a red pen was used to identify descriptive comments, a black pen was used for linguistic comments and a blue pen for conceptual comments. A green pen was used to identify specific areas of the interview itself and my interviewing technique, and a purple pen, was used where I made note of my own reflections related to the participant comments, as I progressed through the transcript. This actually worked well for me, so I used this process with all the transcripts and I found it very useful.

The transcripts were then read in an attempt to identify preliminary themes within the individual transcripts. The process was repeated for each of the transcripts. Any issues, which could be a preliminary theme were listed and a record of the page number and line identifying where this could be found in the transcript was made. These were placed into a preliminary table, which aided in my understanding of this process.

4.4.3: Step Three: Developing Emergent Themes (Clustering)

Step 3 involved exploring sections of the transcript/s in more detail, based on my initial notes and 'drilling down' to a deeper level to enable me to develop a greater awareness of what it was that the participant was trying to say (double hermeneutic). This helped me to understand what the experience actually meant for the participant and enabled me to start to understand their experience of transition as a whole. This part of the IPA process also involves clustering the themes together as a preliminary step in developing the superordinate and subordinate themes. Therefore, Karen's comments were transferred onto post-it notes using the same colour coding format to identify the different levels of analysis. The post-it notes were attached to the wall above my desk to enable me to view them readily. This was a useful process, as the post-it notes could be reshuffled and moved around on the wall, grouping them together to help

formulate themes. A scanned photograph of the post-it notes is presented in Appendix 10.

4.4.4: Step Four: Presenting Themes in a Master Table

Once the transcript for each of the participants had been individually analysed, the transcripts were reviewed to identify any recurring themes within the dialogue. A black felt pen was used in the left hand column of the transcript to identify these emerging themes. At this point, a highlighter pen was also used to identify any issues that 'stood apart' or did not really 'fit' (polarisation) with the rest of the transcript (Smith et al. 2009). These anomalies are also sometimes referred to as 'negative cases or divergent themes' as they are issues / topics that are of particular concern or relevance to the participant and, as a consequence, it is important to identify them within the presentation of the data (Smith 2011). Thus, the participant's exceptional and unique experiences, or experiences that were clearly important to them were also highlighted. Following the formulation of the emergent themes, these were reviewed further to formulate the superordinate and subordinate themes and these will be identified in Chapter Five.

4.4.5: Steps Five and Six Replication and Reviewing

Where there is more than one participant, Step 5 of the IPA process, is a replication process. Therefore, Stages 1 – 4, including the use of coding with coloured pens and using post-it notes, were repeated in exactly the same way for all of the remaining younger participants, (Ben, Molly and Katie) and occurred in the order that the interviews had been undertaken. The only variation to this was Molly, as she was the only participant who was interviewed twice. Although Molly had been officially transitioned at the time of her first interview, she had not been hospitalised for eighteen months, so she had not been admitted to adult services at the time of the first interview. Therefore, the content of her first interview was limited, and the results from both interviews were combined.

Step 6 of the IPA process involved reviewing the notes made from all of the individual interviews, to look for commonalities and patterns, or aspects that stood out as being different. This enabled the similarities across all transcripts to be identified and clustered together within the participant groups. Additionally, as a continuation of the funnelling process, the subordinate and superordinate themes were reviewed at this point and where appropriate, they were combined.

The analysis of the parental interviews occurred in exactly the same way as the young people's interviews. The same process was repeated with the transcripts of the parental interviews and again these were undertaken in the same order as the interviews had taken place (Jenny, Jeff, Sally and Carol). However, with this set of data, Jenny's transcript was used as the baseline, as she was the first parent to be interviewed.

4.5: Chapter Summary

This chapter has provided a detailed account of IPA, which is the research methodology for this study, outlining the three main components; phenomenology, hermeneutics (and the double hermeneutic) and ideography. The research procedure was outlined including the sample, and the relationship between the participants, where appropriate, was set out in a table to add clarity to the information. Additionally, issues surrounding recruitment and the process of data collection were also identified. Data analysis was discussed in some detail and the six steps of the IPA process were identified. Potential ethical issues were highlighted and the difficulties surrounding the recruitment of participants was discussed, including negotiating access to participants, gate keepers and over researched groups.

The key messages from this chapter are that

- Recruitment to this study was lengthy and problematic.
- Gatekeepers have the ability to facilitate and impede access to participants.
- Ethical approval was granted and ethical issues were addressed.
- Eight participants from within Wales were recruited to the study.
- IPA was identified as an appropriate methodology to use within this study.

In the following chapter, (Chapter Five) the participants will be introduced in more detail and the results from the young people's data will be presented using the IPA format.

Chapter Five Data Management

5.0: Introduction

As they progress through life individuals are not passive recipients of what goes on around them and as they experience different situations, they develop the ability to make sense of these experiences by forming their own individual life stories in a way that they are able to understand and make sense of themselves (Brocki and Wearden 2004). Within IPA, the aim of data analysis is for the researcher to become as familiar as possible with the individual experience (life story) of the participant, so that it is the participants' own individual experiences that are being related (Smith et al. 1999). To enable this IPA has three main approaches these are; phenomenology, interpretive and idiographic and have been outlined in more detail in Chapter Four.

This chapter will present the processes used to analyse the data, these being descriptive and conceptual analysis. The linguistic data and analysis will be presented later in this thesis in Chapter Eight.

The process for managing the data generated from the interviews involved three levels of analysis (Smith et al. 1999). This is consistent with the 'funnelling down' method of analysis outlined within the IPA process, which enabled the 'drilling down to a deeper level of analysis. The three levels of analysis involved:

- Exploring individual idiographic experiences, descriptively and conceptually and identifying themes.
- Examining the experiences of the participants and identifying the shared themes in which to locate the discussion.
- Exploring an event ('divergent theme') that was significant and unique to one of the participant's cases.

The step by step process of IPA analysis was outlined in detail in Chapter Four, section 4.5, with an example of the transcription grid provided in Chapter Four Table 7.

5.1: Descriptive Data Analysis

5.1.1: Overview

Following repeated reading of the transcripts and listening to the audio tapes, the first step in the analytical process was to describe the content of the interviews. The aim of this was to develop an understanding of the individuals experiences by recognising specific words, phrases or stories they related within the interview that were important to them. Initially these issues were taken at 'face value' and there was no attempt made to interpret these in any way. This is in line with the phenomenological aspect of IPA. This process aimed to develop an understanding of what it was that had impacted on the experience of the participants, as well as developing an understanding of their own individual experiences. The main focus of the analysis at this point is the *individual* and their own unique experience. Once the preliminary themes within the transcripts had been identified, using notes and 'spider diagrams', tables were developed which recorded the individual responses for each of the participants within the study. These tables were used to develop the superordinate and subordinate themes, reflecting all the participant experiences, these were taken forward into the discussion chapter for further consideration.

To maintain confidentiality and anonymity (NMC 2015) and in keeping with ethical requirements, all of the participants were provided with a pseudonym. There was no process involved, the names were randomly assigned to each participant. In relation to this need for anonymity, other information presented is on occasion deliberately vague, as it may be possible to identify some participants by job description or location.

5.1.2: Descriptive Analysis: The Process

Smith et al. (2009) suggest that there is no right or wrong way to undertake IPA, and encourage researchers to be creative in their approach to IPA analysis. However, for this study, as a novice researcher, the process for this study was as outlined by Smith et al. (2009) to; familiarise myself with the data, identify preliminary descriptive themes from each participant story, cluster the themes together, construct a summary table of the preliminary descriptive themes and because this was a study with, multiple participants, integrate the themes together. A detailed description of the six step IPA process has been provided in Chapter Four. The following section identifies the detailed approach to the descriptive data analysis undertaken in relation to this study.

The reason not to use a software package was outlined in Chapter Four, therefore following the IPA process also outlined in Chapter Four, the first step was to become familiar with the data. Therefore, I repeatedly listened to the audio recorded interviews and made hand written notes, which were then typed up into a grid format (example Table Seven). For accuracy, and closely adhering to the IPA format, the recordings were then listened to again, in conjunction with reading the typed notes, to ensure that the details had been accurately transcribed. Once I was assured that they were accurate, the transcripts were read repeatedly to enable me to become familiar with the content. This enabled me to connect with, the data and the participant stories.

Step two of the IPA process is to identify preliminary themes (Smith et al. 2009). Therefore, Karen's transcript was analysed individually and annotated using different coloured pens to identify descriptive (red), linguistic (black), conceptual (blue) comments as outlined in Chapter Four, section 4.4.2.

The preliminary themes from the first transcript (Karen's) were then recorded and the process was repeated for each of the transcripts in the order that the interviews had been undertaken. The resulting issues / themes from these notes were then placed into a preliminary table (Table 11 Chapter Six). Karen's individual comments were then transferred onto post-it notes using the same colour-coding format to identify the different levels of analysis. The post it notes also helped with the clustering of themes (step three), later in the process.

Following the scrutiny of Karen's transcript, the process was repeated on an individual basis for all of the young people and parental participants in this study. This process occurred in the order that the interviews were undertaken, so for the young people this was Ben, Molly and then Katie. For the parents, this was Jenny, Sally, Jeff and finally Carol, and keeping to this format, this is the order the data has been presented in this thesis. Throughout this process any issues, which were identified as preliminary or emerging themes from each of the individual transcripts were compiled on a separate list. This was a lengthy but meticulous process that was undertaken in conjunction with returning to the audio recordings and repeatedly listening to them at all stages of the analysis.

The printed transcripts were also shared with, and explored by, an independent researcher and a meeting occurred following this to compare and discuss the

preliminary themes drawn from the literature by both the independent researcher and myself. This aided in validating the process regarding the way in which the themes had been identified.

Step three in the IPA process involved deeper exploration of the transcript/s by 'drilling down' to develop a greater understanding of the participant experience of transition (Smith et al. 2009). Step three also involved clustering the themes together to enable the development of the superordinate and subordinate themes. Once the transcript for each of the participants had been individually analysed in detail, this completed the idiographic process (Smith 2004).

The transcripts were then compared with others in the same group (young people or parents) to determine any shared experiences or differences or as Smith describes "convergences and divergences" (p41), and a black felt pen was used in the left hand column of the transcripts to identify these. Once this had been completed and for my own clarity, I developed a simple diagram or mind map for both the young people and parents, again using different coloured pens, which helped me draw the emergent themes together (Appendix 11 / 12

Once the shared experiences had been determined, it made it easier to identify any issues that 'stood apart' or did not really 'fit' (polarisation) with the rest of the transcript (Smith et al. 2009). These anomalies are sometimes referred to as deviant or negative cases as they are issues that have a particular relevance to the participant, so it is important to identify them within the presentation of the data (Smith 2011). Consequently, the unique experiences of the participants were also highlighted.

Once the similarities and differences had been explored, the themes, were reviewed further to formulate the superordinate and subordinate themes, this will be discussed further in Chapter Six.

5.2: Summary

To summarise, the analysis of the results from this study, following the IPA format employed a number of specific steps;

- Listening to the audio recordings.
- Typing up the transcripts using a five column format.

- Annotating each of the transcripts independently using multi coloured pens.
- Using post-it notes to collate the participants descriptive comments.
- Developing a 'mind map' of preliminary themes.
- Reviewing the audio tapes frequently to remain connected with the participant's stories and to identify any areas where linguistic aspects could be located and explored.
- Further develop superordinate and subordinate themes for each participant.
- Compare the themes across the YP and parents experiences and identify the differences and similarities within the participant's stories.
- Establish a list of shared themes.
- Identifying the unique or 'divergent theme'.

This process of descriptive analysis aimed to become as close as feasible to the participant's experiences from their own perspective and using this to help me develop my understanding before moving onto the interpretation of their experiences data in Chapters Six and Seven.

5.3: Conceptual Data Analysis

5.3.1: Overview

The main aim of researchers who use IPA is to examine the way in which people make sense of their own life experiences, how they conceptualise it (Pietkiewics and Smith 2014). Therefore, the researcher plays an active part in accessing the individual's own life world and, through interpretation of the information, that in turn, the researcher is able to make sense of the participants own life world experience (the double hermeneutic). Although the researcher will never have a first-hand experience of the situation being explored, they should aim to get as close as possible to the participants viewpoint (Smith et al. 2006) or in other

words take time to try and walk in the participants shoes for a short time (Pietkiewics and Smith 2014).

It is only when the idiographic analysis of each single case has been undertaken that the second part of the process, the conceptual or cross case analysis (Smith 2004) can be achieved. Conceptual analysis involves reviewing the transcripts as a whole to determine any connections between the individual emergent themes. Smith et al. (2009) identify this as abstraction, the themes are clustered together by placing “like with like” (p96). These ‘clusters’ are then drawn together (convergence) to reduce the overall number of themes (subsumption) and to develop the hierarchical superordinate and subordinate themes (Biggerstaff and Thompson 2008). Through the process of convergence and subsumption, divergent (polarisation) themes can also be determined and this is also where the issues that really stand out to the individual (deviant / negative cases) can be identified (Smith 2004).

Additional steps in this process include contextualisation, which involves developing an understanding of the participant’s background story from both a local and a professional perspective, numeration, which considers the regularity that a theme is referred to and could indicate its importance to the participant and function, whereby some themes can be viewed as having a particular function over and above what the participant is actually saying. An example of this is where the participant could say something to elicit sympathy from the researcher (Smith et al. 2009) and it is possible that this occurred in one of the interviews (Sally) within this study.

Smith et al. (2009) identify that these analytical approaches can draw the participant story together and develop a more in-depth understanding of the data and thereby, the participant experience. Although the IPA process was originally developed for use in psychological research, and as a consequence, most of the examples presented by Smith et al. (2009) and a considerable amount of other IPA research (Brocki and Wearden 2007), focuses on health psychology. However, the step by step approach to IPA is flexible enough to enable it to be used in other healthcare disciplines. Indeed according to Biggerstaff and Thompson (2008), the flexible approach to IPA would make it appealing to healthcare researchers and Pringle et al. (2011) identify that IPA is now

increasing in popularity within the healthcare setting. This makes IPA an appropriate choice to use within this thesis.

5.3.2: Conceptual Data Analysis: The Process

IPA has been developed from elements of both phenomenology and hermeneutics and as such focuses on the interpretation of the lived experiences of individuals; in this study, young people with CF and parents. To arrive at the findings, the process of data analysis has moved from the descriptive to more in-depth conceptual analysis, from an individual to shared understanding of the participant experience. The thesis needs to enable the reader to develop an understanding of what living with CF is like for the young people who have this condition and parents, as it is only through this that their stories will be heard.

Describing the participants experience accurately can be difficult, but interpreting what has been said is even more complex. As a nurse with many years' experience of working with young people, many of whom had CF, I am also conscious that my own professional experiences and knowledge have the potential to influence my interpretation of the data. Therefore, I remained focused on the experiences of the individual. To ensure I did this, I acknowledged my own preconceptions and made sure that I became immersed in the data by following the process outlined in section 5.1.2. The funnelling down process also provides depth to the interpretive element a deeper level of understanding, whereby specific situations described by the participant that have particular meaning or significance for them can be identified.

The linguistic elements within the participant's experiences were also identified and this provided added meaning to the participant stories. The use of language was also examined and this will be discussed later in this thesis (see Chapter Eight).

According to Smith et al. (2009 p28) the hermeneutic cycle is "the dynamic relationship between the part and the whole at a series of levels" and provides an example of this in the following chart.

The part	The whole
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre [whole body of work]
The interview	The research project
The single episode	The complete life

(Smith et al. 2009 p28)

Smith et al. (2009) use this comparison to illustrate the close knit relationship between the part and the whole or the individual and the complete experience. Therefore, the principle of the hermeneutic cycle is that to understand the whole, one must first understand the part and to understand the part, the whole also needs to be understood. Smith et al. (2009) use the analogy of words and sentences as a good way to explain this. In the English language several words look and / or sound the same, but would have very different meanings when placed within the context of a sentence. In the same way, in IPA, the whole is disassembled into parts, and then reassembled back into the whole as demonstrated in the following two chapters of analysis.

5.4: Reflection

Larkin et al. (2006) identify that the “balancing act” (p103) required in undertaking the IPA process is not always easy for the novice researcher to achieve and I would agree with this. On reflection, the analysis of this research has not been an easy process and there have been times when I have struggled with the concepts of IPA. Usually I work well with process and structure but this for me has been the exception. Although it appears to be a sequential step by step process, I personally have found the IPA process to be convoluted and far less straightforward than I originally thought. I acknowledge that this, for the greater part, relates to my inexperience as a qualitative researcher, but it has nevertheless caused me considerable anxiety and frustration. However, once started on this path I felt that it was important to continue. The distinctive aspect of IPA and what makes it stand out from the crowd, is the double hermeneutic, the interpretation of the interpretation. As this research relates to the individual experiences of young people with CF and parents, and as IPA aims to interpret

and understand the experiences of individuals, it is appropriate to this study and was worthy of perseverance.

One of the biggest challenges I faced was to keep the role of the practitioner and researcher separate from each other. As a practitioner with considerable experience of working with young people who have CF and their parents, I believe that this helped me when I was analysing the transcripts. I was able to read into what the participants were saying as I could draw on my experience and knowledge of CF to understand how this affected individuals and their families from a healthcare professional perspective. However, this also became a hindrance, as on reading the transcripts it was tempting for me to read more into what the participants had said because of my background knowledge, particularly with regard to when they were discussing the effects of CF on the individual and their family.

Conversely, trying to view the situations presented purely as a researcher was challenging and I did not anticipate how difficult this would actually be. What hindered me was going into this research *thinking* that my background would be helpful to me as a researcher. To help me with this I had to keep reminding myself to take a step back and to consider what was being said and not what I could 'add' to that or 'read into' with my practitioner hat on. Consequently, I constantly kept referring to the IPA guidance to try to keep refocusing myself as a researcher and not a practitioner.

Additionally, some of the interviews were particularly challenging for example, Ben appeared to be a little distracted at times. I am not sure why this was the case, possibly because he was a young man and it was the way he communicated, or it may have been because it was via telephone or because I was an unknown adult seeking information. In contrast, the young women were more easy to talk to and provided a wealth of information.

Personally, I experienced a range of emotions when I undertook the interviews and listened to the audio tapes, which I did not really expect. For example, I was very uncomfortable when I replayed Molly's interview as I could not get away from the feeling that the 'night visitor' actually knew what he was doing and that his actions were predatory in nature. However, more than anything else

throughout all of the interviews, I was inspired by the courage and optimism of the young people who took part in this study.

5.5: Chapter Summary

This chapter has provided a detailed account of the way in which the data for this study was managed using the IPA process to undertake the descriptive and conceptual data analysis. The key messages from this chapter are:

- Using the flexible approach of IPA enabled the participants to discuss what was important to them as individuals.
- Through the IPA process of funnelling down the data, the subordinate themes were outlined and identified.
- The process of undertaking the data analysis was identified and this was presented from both the young people and parents perspectives.
- The conceptual data analysis process was outlined and discussed.

Chapters Six and Seven will present the descriptive accounts of the young people and the parent's experiences of transition from child to adult services.

Chapter Six

The Young People

6.0: Introduction

Within this chapter a descriptive account of the experiences of the young people who participated in this study will be provided. A brief biographical description of each of the young people will be provided prior to discussing their individual experiences. Then, the patterns and connections identified between them as a group will be described with the aim of presenting their shared experiences. Any quotes presented in this chapter are presented verbatim, which includes all pauses and paralanguage.

6.1: Idiographic Experience

Karen

Karen, was aged 26 years at the time of her interview. She transitioned when she was 19 years old, and is the only participant in the study to have transitioned from an adolescent ward at the children's CF centre to the adult CF centre. Karen lives in her own home with her partner and at the time of the interview, they were considering starting a family. Karen has one sister who does not have CF.

Karen appears to be a quiet and self-assured individual who has a considerable knowledge of CF and the management of this condition and she uses this knowledge to support other people with CF. By mutual consent, the interview took place in her own home and she was very welcoming and very easy to talk to. Her responses were confident and knowledgeable and it became obvious that she was used to discussing CF and a range of issues surrounding this condition on a regular basis.

Karen currently works part time in a flexible position. Consequently, she tends to work from home for the majority of the time, but this depends on her overall health. Although Karen undertook and completed a degree in physiotherapy, she does not work in this area as she found it too difficult to manage the clinical aspect of this role. Since the interview, and whilst this study was being undertaken Karen's health deteriorated considerably and she eventually underwent a bilateral lung transplant in June 2015.

As identified in Chapter Five, the first step in analysing Karen's transcript was to make a table of preliminary notes and identify potential preliminary themes and this is presented below.

Table 8: Preliminary Notes/ Themes: Karen

Karen's Comments	Preliminary Theme
I was kept there [children's services] for quite a lot longer than I probably should have...	Kept too long
I had introduction clinic appointments with the adult team.	Preparation
I think I had a bit of a period of instability I think	Unsettled
For the first 10 minutes of the consultation...come into the room on your own. So any problems or questions that I needed to say, I would say them rather than my mum.	Preparation
Moving to a new hospital and new team	Changed hospitals
I was moving out... to university, so I had to manage a new team doing normal independent things, like shopping, washing, cleaning...	Personal life changes
so when I went to the adult team, the whole appointment set up was completely different	Changed hospitals
I never had any of my IV care like on a children's ward or anything...I was always cared for on the YPU...	Location of care
I don't think it hit me until the first year of uni.	Delayed response
They expect you to know, because you should know... you take that medication every day and you should be in control of what you take.	Taking over own management
Well just to say that as I've built a fantastic relationship with the paed's team, I think I've built a fantastic relationship with the adult team.	Building relationships
I had always appreciated, how good my relationship was with all of the clinical team. [CYP].	Good relationships
It was hard, really hard, a lot of change that happened in a short period of time.	Unsettling changes
Like I always look back on my transition as quite a good experience...it's only afterwards it affected me I think.	Delayed response
I think it was a big change and I think I was, I was a bit upset. I felt like I was dumped in this new hospital with this new CF team.	Felt abandoned
I don't think she meant to, but she [mother] really was involved in my hospital appointments and I think she sometimes forgot that I had a voice.	Mother's involvement
She [mother] just wanted to make sure that I was having the best level of care and that we were doing everything we could do to maintain my health.	Mother's continued involvement
And you know, I keep her [mother] in the loop, if anything major or different happens.	Keeping mother informed

Uhm, it was really hard for her [mother] I think, I think for the first year. Really kind of cut up about it, uhm, but she is used to it now.	Difficulties for mother
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Using the preliminary notes also enabled me to expand on the issues / topics with more extensive quotes from each of the young people. Therefore, starting with Karen, the preliminary notes followed by more extensive quotes will be presented for each of the young people in the following section. This starts with Karen's perception of the information she received prior to transition.

Karen identifies that she was prepared in some way before she move to adult services. This was predominantly undertaken in the outpatient department:

I remember [named CF nurse] would say (pause) uhm, for the first 10 minutes of the consultation you'll come into the room on your own. So any problems or questions that I needed to say, I would say them rather than my mum.

Karen's impression of transition was initially ambivalent but on further discussion she identified that she did feel that consideration was not given to the other things that were happening in her life at the time.

I think because the independence wasn't in moving to a new hospital and new team, I was moving out. I was moving to university, so I had to manage a new team doing normal independent things, like shopping, washing, cleaning. Starting a new uni course, a full on uni course, stressful, demanding uni course. I think it was too much at one time I do, and manage a new condition too you know. Uhm it was only about 6 months before I got diagnosed with CF related diabetes and actually as soon as I moved to the adult team, I needed a new port.

The transition process did appear to have an impact on Karen although she recognised that she did not necessarily identify this at the time.

I don't think in my circumstances, like I always look back on my transition as quite a good experience. I think it's only afterwards it affected me I think... So I think it was quite stressful. Uhm, because it was just different, and was all stuff just happening all at once. And actually, it's only talking about it now, that I realise why I struggled so much in the first year. I really felt it was hard in the first year of uni (long pause – thinking) it was hard. I think it was just one too many things happening at once... 'cause it wasn't just moving from the paed's team to the adult team, it was actually moving hospitals and I think over the 19 years that I had been at the [named hospital], I had got so used to the way that the hospital worked.

One of the issues that Karen identified as being important when she transitioned to adult services was the ability to form a relationship with the staff in adult services:

I think I had always appreciated how good my relationship was with all of the clinical team [in children's services]...It's like anything, if you start a new job or go somewhere new you always worry, oh gosh, am I going to have a good relationship with the people that I, you know, probably will have to spend a bit of time with.

However, she did go on to identify that this concern was unfounded:

Uhm, well just to say that as I've built a fantastic relationship with the paededs team, I think I've built a fantastic relationship with the adult team. Uhm, it's taken...it did take a little while, because you've got to get to know people and get to feel comfortable, but yeah, things have been ok with the adult team.

It is clear from Karen's experience of transition that differences were noted between child and adult services.

The whole appointment set up was different... I think that there's a lot in adults that's completely different – not spoon fed any more.

However, Karen also gave the impression that she was able to manage her own care and that she did so on a number of occasions.

I could reel off my medication any day now. I know what I'm on, what the dosage is and it's what's expected of you in adult...because you should know, you know, you take that medication every day and you should be in control of what you take...I can do the majority of physio myself and actually I've got kind of adjunct physio. I've got Acapella®, PEP™ mask... So things like that really, uhm (pause), you know I was in control of taking my medications. I was in control of doing my physio... and, you know, not that you can't ask for help, because you can (pause) but you are expected to be independent.

In the quote above, Karen recognises that she is able to manage her own care and seems confident in doing this. However, there appears to be some contradiction here between being independent, which is expected and being able to ask for help. Although Karen suggests that you can do both, the hesitancy between where she states you can ask for help and the expectation of being independent, although brief, could suggest that her experiences may have been different.

With regard to the impact that transition had on her family, Karen related this to her mother and identified that:

She was really upset, really, really, upset and I think she still finds it a bit weird that she doesn't come along to appointments with me now, because she wants to know the ins and outs...Uhm, it was really hard for her I think, I think for the first year. Really kind of cut up about it, uhm, but she is used to it now.

Although Karen was clearly ready to take over the management of her own care, she recognised that this was difficult for her mother but suggests that she is “used to it now”.

Ben

Ben was 19 years of age at the time of the interview and 18 years old when he transitioned from a DGH to adult services. Ben is single and lives at home with his mother who is divorced. He has two younger siblings, a brother with CF and a sister who is unaffected by this condition. Ben is in full time education (College of Further Education) studying Sports Science, which he enjoys, he also enjoys socialising with friends. Ben has a part time job in a fast food outlet near his home and fits this in around his college commitments.

Ben was not particularly communicative and although he had agreed to be a participant, at times throughout the interview it was difficult to engage him in conversation. Many of his responses were limited and consequently, the depth to the discussion was reduced. On occasions throughout the interview, I could hear background noise such as an incoming text alert from a mobile phone. This was coupled with some pauses in the interview, when Ben appeared to be distracted, so I suspect that there were times when Ben was not giving the interview his full attention. In general, Ben did not seem overly concerned with the transition process and during the interview, the only time he became animated was when he discussed increased socialisation and improved facilities within the adult setting.

Table 9: Preliminary Notes/ Themes: Ben

Ben's Comments	Preliminary Themes
It didn't really bother me.	Ambivalent
They transferred me when I was 18 like, I just went over.	Transition Prep
I was fine about it, but like the distance, it's a	Change of location

pain.	
We went down for like a meeting. One of the team...took us down and then she just showed us around...	Transition Prep
I think so, yeah, yeah... it was like enough info....	Information
It wasn't that difficult to find like, the CF ward is marked in orange so all you've got to do is walk down the corridor and you are there.	Finding the new ward
Like I do all my stuff now and again but like I won't do as much as other people because like I am working as well.	Fitting it all in
I ring them for appointments and stuff	Organising self
It's the same for my mum [travel] it's a bit of a pain for her.	Travel issues for mother
We [mother] go down every month.	Mother's continued involvement
Yes she [mother] still helps out.	Mother's continued involvement
Like in the [children's ward] there was no one my age.	Loneliness
The adult ward is better. Like you get more freedom. Like you had your own room in both hospitals, but like, I don't know like, there is more freedom, like you could go wherever you want. Yeah, they let me leave whenever I want as long as I am back in time for my antibiotics and all the physio stuff that's fine.	More freedom in adult setting
When I go in for two weeks it's hard for her [mother] to come down..	Problems visiting
Yeah the doctors in [named DGH] were nice like they took care of me really well, but it's the same in [named adult hospital].	Relationships with staff
There's still really good nurses there [adult hospital] and they specialise more in CF.	Specialist staff

With regard to the transition process itself, Ben was brief and succinct and identified that:

They transferred me and then when I was 18 like, I just went over

The majority of Ben's interview was very 'matter of fact' and in relation to how he felt about transition he only made two short comments suggesting that in the main his only concern was needing to travel a greater distance to the adult hospital. As he identified that:

It didn't really bother me.

Yeah, it's nothing about the move...they were welcoming and all that...it's just the location that's all.

Ben was also involved in managing his own care and was able to fit this in around his busy lifestyle although he does seem to have difficulties with this:

Yeah with my college and stuff it's hard to do my physio and stuff it's hard to fit it all in.

Like I do all my stuff now and again but like I won't do as much as other people because like I am working as well, I go to work straight after college see, so it's hard.

I mainly just go to the gym, do stuff in college – like we are training almost every day and going to the gym in college.

Ben did not discuss his relationship with staff as such, he placed this more into the context of the care the healthcare professionals provided for him.

Yeah the doctors in the [named hospital] were nice, like they took care of me really well, but it's the same in [named adult hospital] there's still really good nurses there and they specialise in CF.

Moving to adult services was clearly a perceived improvement for Ben and he identified some of the differences between child and adult services.

Like in the [children's ward] there was no one my age.

The adult ward is better. Like you get more freedom. Like you had your own room in both hospitals, but like, I don't know like, there is more freedom, like you could go wherever you want. Yeah, they let me leave whenever I want as long as I am back in time for my antibiotics and all the physio stuff that's fine.

Ben's first comment suggests a sense of loneliness and isolation when he was admitted to children's services and it is perhaps because of this that he appeared to be so impressed with adult services. One issue that was clearly of importance to Ben was that of having more freedom in adult services.

When it came to discussing the impact transition may have had on his mother, Ben identified that the greater travelling distance to reach the adult hospital was also of concern to her:

It's the same for my mum [travel] it's a bit of a pain for her like but now I can drive it's not too bad.

When I go in for two weeks it's hard for her to come down. She's got two other kids.

Ben's interview was the second interview I undertook, it was challenging and a stark contrast to the interview that I conducted with Karen, which was much easier and had a certain 'flow' to the discussion. The conversation with Ben was much more stilted and when the interview ended I felt that there were areas that I could have explored that I did not. However, Ben was clearly distracted and seemed to want to get the interview completed as quickly as possible.

Molly

Molly was 18 years of age at the time of the interviews and she had recently made her transition from the children's to the adult CF centre. Molly is the only participant who was interviewed twice, as at the time of the first interview, although she had been 'officially transitioned' she had not been admitted to adult services. Therefore, a subsequent interview was arranged. Molly lives at home with her mother (also divorced) and two siblings, an older brother and a younger sister, neither of whom have CF. Molly is completing her education in a College of Further Education.

Molly seemed to be a pleasant young woman with a bubbly personality. Again, she was not particularly articulate in relation to her choice of words and as with other young people of her age, she favoured the use of the word 'like', which was punctuated repeatedly throughout her dialogue. However, she knew what she wanted to say and did so. At times, she gave the impression of being excitable and a little immature but this was belied as she progressed through the interview, when it became apparent that she actually had 'an old head on young shoulders', which is typical of many young people with a chronic illness.

Table 10: Preliminary Notes/ Themes: Molly

Molly's Comments	Preliminary Themes
They [children's services] gave me lots to read.	Information
I've just been nervous about moving over.	Apprehension
They just said, you know 'you're moving hospitals'...	Information
I've been to have a look at the wards...I've met some of the staff on there [wards] and... some of the CF team.	Information
My mum stays with me so it's like for the two weeks when I go in, the difference like, she can't come in with me...cause I'm used to her being there like.	Differences causing apprehension
I had an admission but I didn't stay on the ward [CF unit] as it was full.	Alternative ward
I know they [the nurses] forgot like when they said 'I'll go and bring your nebulisers' ...and it was an	Nursing management

hour or two before they remembered and that was ...a bit you know slacky, but other than that really good.	
Yeah she's finding it strange you know when we move over and she can't stay there.	Mothers feelings
She [mum] was leaving about half ten, eleven o'clock at night and coming in seven o'clock in the morning and then she did that for two weeks as well.	Mothers continued involvement
Yeah, the nurses said, some nurses were like, 'Oh your mother can stay in with you', and I thought that's OK then other nurses said no.	Nursing management

Molly's experience of her transition was varied and much of her second interview was taken up with a situation she had experienced during her first admission to adult services. This will be identified later as a 'deviant or negative case'.

Molly did not spend much time discussing her transition preparation and she only identified that she had

... met some of the CF team and they seem nice

However she did identify that she was apprehensive about moving to adult services and suggested that there was a particular reason for this.

I've just been nervous about moving over...Just moving I think 'cause mum stays with me, so it's like for the two weeks that I go in, the difference like, she can't come in with me

The fact that her mother was unable to be resident with her during her admission to the adult hospital was of great concern to Molly as she had not stayed in a hospital on her own prior to her first admission to adult services.

Molly also commented on some of the differences she had noted regarding her care in adult services, particularly in relation to her medication.

I mean the care was really good I know they forgot like when they said 'I'll go and bring your nebulisers' they'd forget and it was an hour or two before they remembered and that was you know, a bit you know slacky, but other than that really good.

It appears from the above comment that Molly was trying to be diplomatic and place a positive slant on her care by stating that her care was "really good" although she does not elaborate on the really good care, she does indicate that the staff forgot to administer her medication. As this is somewhat of a

contradiction, it is possible that Molly did not want to make what could have been perceived as a complaint about the staff.

Molly also identified some inconsistencies in the information she was provided with, which again relates to her wanting her mother to stay with her when she was in hospital.

Yeah, the nurses said, some nurses were like, 'Oh your mother can stay in with you', and I thought that's OK then other nurses said no [emphatically]. Which they should all have a meeting and say no or yes 'cause it's not fair telling me yes and then other people telling me no because I was like really thing about it. Like I didn't really, I wasn't bothered, I was bothered actually.

This inconsistency was clearly difficult for Molly to contend with and she uses a colloquial term that young people use to describe their feelings when she said “*I wasn't bothered*”, which could suggest that she was trying to put up a ‘brave front’ with regard to the situation. However, she then changes this to “*I was bothered actually*” as an indication that she *was* actually unhappy with this situation.

This theme was continued when Molly described her mother's feelings about transition when she suggested that:

Yeah she's finding it strange you know when we move over and she can't stay there.

Considering all this, it is clear that Molly was more than a little concerned that her mother was unable to stay with her as she kept returning to this theme in different contexts. This is particularly so as she identified that her mother was supporting her by staying at the hospital for as long as she possibly could during the day:

She [mum] was leaving about half ten, eleven o'clock at night and coming in seven o'clock in the morning and then she did that for two weeks as well.

The above statement also demonstrates Molly's mothers commitment to remaining involved in her daughters care following transition.

Katie

Katie is aged 33 years and she transitioned from a DGH (not the same one as Ben) when she was 19 years of age. Katie was the furthest away from transition

in comparison to the other participants and although she did not really fall into the 'young person' category, she was eager to participate and overall, had a good recall of events. Katie had married not long before the interview took place, and she now lives in her own home with her husband. Although this is some distance away from her parental home, it is within an easily commutable distance and she remains in close contact with her parents.

Katie seems to be a confident and outgoing young woman with very much of a 'let's get on with life' attitude and it becomes evident that she does not allow CF to influence her life. Along with her parents, she is very involved in fundraising both for the adult hospital and for the CF Trust. This has included a range of activities from cake stalls and fetes to bungee jumping and sky diving, all of which Katie has participated in.

Katie also undertook a degree but (like Karen), does not work within her field of study, although she does use aspects of her degree within her current work. Due to some difficulties with her last employer, who was not particularly sympathetic of her need to take time off when she was unwell, Katie is now self-employed as a graphic designer and works from home. Although she finds this more conducive to managing her CF, she does admit that she misses the companionship of work.

Table 11: Preliminary Notes/ Themes: Katie

Katie's Comments	Preliminary Themes
It happened very quickly...there wasn't any build up to it.	Process
From what I can remember the transition period at the time was very, very easy.	Process
Yeah, a huge difference. I remember that actually quite well. Yes, I remember it was the best thing since sliced bread.	A good thing
Obviously background conversations go on but I am not sure that we were aware of any of those.	Before transition
I am not quite sure, you get comfortable with the team that you have been with and how things are done there.	Familiarity
Yeah, I was really anxious, uhm intrigued, a bit of a mixture really. Uhm, you don't really know if you're ready until the day and actually then, I discovered I was.	Anxiety and readiness
I'm quite a laid back person, so for some people it's quite a big deal, but I've taken things in my stride.	Not concerned
I had got so used to the way that the hospital worked.	Familiarity
I do them myself, yeah [IV antibiotics].	Expert patient
When I was with the children's centre, I could pop back every day even if I wasn't staying in, whereas with the	Differences between services

adult centre you're kind of left to your own devices there with home IVs.	
But I live in [named location] now, so popping back [to adult services] now is not an issue.	Moved closer
...and they [adult staff] were fabulous, friendly and helpful...	Relationships with staff
When I did move over to the adult team although I was self-sufficient as a patient, you know I was really independent it was a bit of a shock.	Differences between services
Uhm, they could see that I was happy and comfortable, confident with the team, but yeah, I don't know how they felt about the fact that I was more independent.	Taking more responsibility for care
They reacted quite well, uhm, I think they felt they had a support network here [adult services].	Parents response to transition
Although even now aged 33 my parents are still involved quite a lot and that's the way I want it.	Continued parental involvement
I think that I still have that independence and that was a good mix of that there [adult hospital] straight away.	Taking more responsibility for care
I think I did have some information, leaflets and things yeah.	Information

With regard to her overall transition experience, Katie identified that she felt ready for the transition to adult services.

I am not quite sure you get comfortable with the team that you have been with and how things are done there. So from that aspect it's hard to let go of past things, but looking back I was reassured and yes, it was the right thing. I was ready.

Despite feeling that she was ready to make the transition, Katie also recognises that there were some difficulties involved with this, including leaving the familiar surroundings of children's services to move to somewhere that is unfamiliar. It is possible here that she is suggesting that this fear of the unknown did cause her some anxiety, but that overall she was ready.

Katie does acknowledge that although she was ready to transition, her parents may not have felt the same way as she suggests that:

Uhm, they could see that I was happy and comfortable, confident with the team, but yeah, I don't know how they felt about the fact that I was more independent.

Katie's readiness for transition to adult services is also borne out in a subsequent statement relating to the post transition period when she was describing the differences between child and adult services.

Yeah, a huge difference. I remember that actually quite well. Yes, I remember it was the best thing since sliced bread.

Katie then went onto suggest that

In a general centre [DGH], perhaps the CF management wasn't as great, you definitely saw a difference in that

Katie appears to be inferring here that she felt the care she was receiving at the DGH was not as good as the care she received when she transitioned to adult services. It is possible, that if this were the case or even if it was only Katie's perception of the situation that it made the transition experience easier for her to manage. However, Katie did identify some negative aspects of care in adult services when she suggested that.

When I was with the children's centre, I could pop back every day even if I wasn't staying in, whereas with the adult centre you're kind of left to your own devices there with home IVs.

What Katie does not articulate here is that when she lived in the parental home, this was very close to the DGH where she received her care, which enabled her to remain in close contact with the healthcare team. However, following transition and on moving out of home, she actually lives fairly close to adult CF services. So the issue here is not that she is not really close enough to "pop back" if she needs to, but whether or not she feels comfortable enough with the staff and the processes in adult services to do this.

Katie has clearly managed her own care for some time including her intravenous (IV) therapy and she recognises that she has been able to do this with the support of her parents. She also indicates that although there have been suggestions made for providing home IV therapy, this has not eventuated and is in line with her earlier comments regarding being "left to your own devices".

I've done home IVs where I can thanks' to Mum and Dad.

I do them myself, yeah. There have been talks of district nurses or nurses coming out but that never evolved that never happened. I've (pause) last couple of years it's gotten more, it's every 8-10 weeks on average.

In the statement above, Katie not only acknowledges that she manages her own care, but also that she needs to do this more frequently. However, it is interesting that she places this in the context of managing her condition as opposed to the

possibility of her condition worsening. Although this seems to be reflective of Katie's attitude towards life in general and her approach to CF in particular.

Although she is able to manage her own care, Katie still acknowledges the contribution both her parents make to support her as she identifies that:

Although even now aged 33 my parents are still involved quite a lot and that's the way I want it.

She then goes onto say that:

They've [parents] always helped me, it's just made it easier for my adult life.

Katie's first comment seems to have a slightly forceful edge to it as she acknowledges her age as well as the contribution her parents still make, but then goes onto say "*and that's the way I want it*" almost as though she were defiant in her attitude towards the convention that once transitioned, parents should not be involved in care and young people should be self-sufficient.

6.2: Summary

This section has identified the individual experiences of the young people within this study. However, when working through these individual themes it became apparent that some patterns were emerging. In the next section and in keeping with the IPA process, the participants shared experiences (convergences) will be drawn together. It was though this process that the unique situation (polarisation) that Molly experienced was identified. This will be described later in this chapter as a 'divergent theme'.

6.3: The Young People: Shared Experiences

Due to their age range (18-33 years), the young people participant group could easily be divided into two sub-groups with the two older participants (Karen and Katie) in one and the two younger participants (Ben and Molly) in the other. On face value, that could present a case against them being a homogenous group, but despite their age differences, they all have two things in common: they all have CF and they have all made the transition from child to adult services. These are the factors that bring them back into one homogenous group.

I also believed that for the purpose of presenting the overall results it seemed logical just to divide the total number of participants into two groups; young

people and parents. Even though Katie (33yrs) does not actually sit within the 'young person' age group it seemed more appropriate to describe all of the participants with CF as young people as opposed to participants or patients, I felt that this would have dehumanised them, which would be in direct opposition to the philosophies of humanistic qualitative research.

Despite the, disparities in ages between the young people, comparisons were identified within the transcripts and the preliminary themes reflect this. Using the process identified in Chapter Five, the comments from all of the young people were drawn together and from this the subordinate themes were identified and are outlined in the table below.

Table 12: Drawing Together Preliminary Themes – Young People

Participant Comments	Preliminary Theme
Kept too long/ information / process / before transition/ information	Pre Transition / Transition preparation/ Transition process
Unsettled / delayed response / unsettling changes/ felt abandoned/ ambivalent / apprehension / differences causing apprehension / personal life changes / a good thing /anxiety and readiness / not concerned	Impact of transition on young people
Building relationships / good relationships / familiarity / conflicting information	Relationships with staff
Difficulties for mother / mother unable to stay/ mothers feelings/parents response to transition	Parental feelings
Keeping mother informed / mothers continued involvement	Continued parental involvement
Changed hospitals / travel issues / finding the new ward / mother problems visiting/ alternative ward / nursing management / differences between services / moved closer/ location of care	Changes / differences
Taking over own management /fitting it all in/ organising self / self-care / taking more responsibility	Managing own care

As identified in Table 13, all the participants commented on all of the issues that were grouped together initially into preliminary and then into superordinate themes. The exception to this was Molly, who was the only participant who did not make any comments regarding managing her own care.

Table 13: Cross Referencing the Preliminary Themes – Young People

Preliminary Theme	Karen	Ben	Molly	Katie
Pre Transition / Transition preparation / Transition process	X	X	X	X
Impact of transition on young people	X	X	X	X
Relationships with staff	X	X	X	X
Parental feelings	X	X	X	X
Continued parental involvement	X	X	X	X
Changes and differences	X	X	X	X
Own Management	X	X		X

Following the development of the preliminary themes, three overarching superordinate themes were identified; Transition, Contexts of Care and Family Issues. These then led to the development of the subordinate themes, and the way in which these sit within the superordinate themes are set out in Table 14.

Table 14: Ordering of Themes - Young People

Superordinate Themes	Subordinate Theme
Transition	Transition Preparation The Transition Process Impact of Transition on Young people
Contexts of Care	Changes and Differences Managing own Care Relationships with Staff
Family Issues	Parental Feelings Continued Parental Involvement

The young people's accounts of transition and the issues surrounding this were all very much grounded in their own experiences. The responses offered by Karen and Katie, the two older participants were sometimes measured and demonstrated a detailed knowledge of their own healthcare needs and CF as a whole. Their approach to transition was more pragmatic, as they viewed it as an inevitable process.

In contrast, the younger participants (Ben and Molly) provided a different viewpoint. For Ben, it was all about improved facilities and a greater sense of freedom than he had been able to experience in children's services. Molly on the other hand, viewed transition with a mixture of excitement and apprehension. In the following sections, the superordinate and subordinate themes will be used to structure the participants shared experiences.

6.4: Superordinate Theme: Transition

Within this study, the impact of transition varied depending on each individual's experience. Only one participant (Ben) did not appear to be affected by the transition process and conversely, although in the pre transition interview, Molly looked forward to making the transition to adult services due to an adverse event after transition her feelings regarding moving to adult services had changed.

6.4.1: Transition Preparation

One of the initial issues for young people is being adequately prepared for making the transition to adult services. The level of written information provided to each individual participant prior to their transition was varied. However, the preparation did appear to include pre-transition visits to the adult setting. Karen stated that prior to transition she “...*had introduction clinic appointments with the adult team*” and recognised that during the ward rounds, one of the children's CF specialist nurses had also tried to prepare her for the move to adult services.

... And [named nurse] would say things like (pause) so what medications do you take then and she would expect me to reel them off.

Ben was one of the younger participants who undertook a pre transition visit under the umbrella of information. However, Ben did not appear to have many expectations with regard to pre transition information and he identified that: “Yeah, it was like enough info” and then went onto suggest that “*I think they done really well by taking me there and stuff and showing me around. That's all I really wanted*”.

Molly, was the only participant who was interviewed twice, the first time when she had been prepared for transition, but had not moved to adult services and the second interview, after transition had occurred. Molly's perception of the information she received was a little contradictory. During the first interview Molly identified that: “*They just said for me to go over and have a look and meet the CF team and stuff*” and that...“*they gave me lots to read*”. However, during the second interview, she suggested that “...*they didn't tell you much they just said, you know 'you're moving hospitals'*”. It is possible that this apparent contradiction was due to the time lapse between the interviews and that Molly had simply forgotten the information she had been given prior to transitioning to adult services. However, it may also have been because throughout the second

interview Molly was distracted with a situation that had occurred during her admission. Consequently, she did not seem to be giving her full attention to the issue of transition.

Although Katie did discuss information, she did not appear to have a good recollection of this as she suggested that, *“I think I did have some information, leaflets and things yeah”*. This is possibly because Katie was the oldest of the participants and therefore, the time lapse since her transition was the greatest.

In relation to transition preparation the shared experiences of this small group were varied, although all participants identified that their experiences of transition were more positive than negative.

The information they were provided with also varied with some participants (Karen and Katie) not being provided with any written information. Alternatively, Molly identified that she had received some written information and Ben could not remember, whether or not he had been given anything to read.

6.4.2: The Transition Process

In relation to the actual process of transition and the way in which this occurred, all of the participants were quite sparse with their comments. Karen identified that:

I was kept there [children’s services] for a lot longer than I probably should have been... there were reasons why I wasn’t transitioned earlier because there was a problem with the adult team. Uhm, they were having quite a changeover of staff.

Ben appeared to view the transition process with a nonchalant attitude as he stated that *“they transferred me and then when I was 18 like, I just went over”*. However, the section *“they transferred me...and then I just went over”* does suggest that some preparations were initiated prior to his 18th birthday. In contrast, Molly briefly describes a preliminary meeting prior to transitioning as she suggested that, *“I’ve met some of the CF team and they seem nice”*.

Interestingly, given that she had the longest time lapse since her transition, Katie was the most vocal on this theme. Initially she identified that *“from what I can remember the transition period at the time was very, very easy”*, but then goes on to say that *“it happened very quickly...there wasn’t any build up to it”*. This

does seem a little contradictory as it implies that the process could have been rushed.

Linking her comments regarding transition preparation, Katie also commented that “*obviously background conversations go on but I am not sure that we were aware of any of those*”, which could imply that Katie and / or her parents, were not included in all aspects of the transition process.

Later in the interview after digressing somewhat, Katie reverted to the topic of her transition and identified that she also met some of the staff in the adult setting prior to transition, although she was not sure whom she had met and when, as she identified that:

I'm not sure if I met everybody before first clinic. I think it was that way around, hence it not being too overwhelming, 'cause I knew who I was going to see at the clinic. I had already met them and I'm pretty sure that's what happened.

Although all of the participants indicated that there was some form of process to their transition, given the scarcity of comments, it is not clear whether these preparations were undertaken in any depth, or to what level the participants were actually included in this.

6.4.3: The Impact of Transition on Young People

Overall, the impact of transition on the participants was variable. On this theme, Karen and Katie were the most vocal, whereas Ben did not appear overly concerned. Molly, identified some anxieties in the first interview, and then recounted an incident in her second interview, that will be identified later in this chapter as it adversely affected her perspective of the adult setting. Early in her interview, Karen identified that:

I think it was a big change and I think I was, I was a bit upset. I felt like I was dumped in this new hospital with this new CF team 'cause I felt like I was (pause) I probably was wrapped up in cotton wool, at the hospital, the paed's centre.

This comment suggests that Karen could have experienced a sense of loss when she left children's services. Additionally, she may not have been as prepared for the move as she originally suggested.

Again, Ben did not appear to be overly affected by his transition to adult services as he indicated that *"it didn't really bother me"*. Ben's main concern was that the adult hospital was further away from his home than the DGH where the children's services he attended were based. Distance was a recurring theme throughout his interview and in relation to his transition he identified that *"yeah, it's nothing about the move...they were welcoming and all that...it's just the location that's all"*.

When Molly was first interviewed she had not been admitted to adult services and at that time, she commented that *"I've just been nervous about moving over"*. However, when this comment was probed further, the main concern for Molly was that her mother would not be able to stay with her in adult services as she explained that:

Just moving I think 'cause mum stays with me, so it's like for the two weeks that I go in [to children's services], the difference like, she can't come in with me [to adult services] no she's not allowed to do that (pause).

This was a real concern for Molly and throughout this section of the interview, she looked visibly anxious and she was clearly not happy about the prospect of having to stay in hospital without her mother being resident and providing support. To compound this, during her first admission to adult services, Molly experienced an adverse event, the event itself will be identified later in this chapter as deviant / negative case. However, the impact this had on Molly was considerable and she identifies that:

Oh every little noise then, I just woke up and I just couldn't sleep for the two weeks because that happened at the beginning of my admission. I couldn't sleep, I just, I don't know, it just scared me I wanted to go home (laughs).

Katie's description of her transition tended to be more drawn out and interspaced throughout the interview. This could have been due to Katie being the oldest of the participants and therefore her recollection of the transition process was not as fresh in her mind. Consequently, her conversation tended to wander and on occasions required her to be manoeuvred back to the topic of transition. However, Katie predominantly identified a more positive transition experience as she suggests that *"yeah, a huge difference. I remember that actually quite well. Yes I remember it was the best thing since sliced bread"*.

Katie appeared to be ready and pleased to be transitioning although she did seem to have some anxieties. This is indicated in her response to what she thought about transitioning to adult services:

Some actual progression, but I am not quite sure, you get comfortable with the team that you have been with and how things are done there. So from that aspect it's hard to let go of past things, but looking back I was reassured and yes, it was the right thing. I was ready.

This is further highlighted in another part of the interview where Katie seems to be suggesting some conflicting thoughts with regard to transition when she suggests that:

I think that's the strange thing, from age 16-18, you know perhaps you want a little bit more independence, but you're not quite ready for the transition, there's a grey area there.

It is evident that with the exception of Ben whose only apparent concern regarding transition was travelling further to receive care, Karen, Molly and Katie, were all affected to varying degrees by the transition process and moving from child to adult services. However, some positive aspects of transition were also identified.

6.5: Superordinate Theme: Contexts of Care

All of the young people within this study identified various issues that come under the heading of contexts of care. In keeping with the other themes, some participants had more to say than others and understandably, their views were varied. However, the majority of participants in this study indicated that in general, they had positive experiences within the adult setting.

6.5.1: Changes and Differences Between Child and Adult Services

All of the young people in this study identified specific differences between child and adult services. In general, Karen's comments tended to focus on the differences she had experienced between child and adult services. Initially she identifies her familiarity with children's services when she suggested that:

I had got so used to the way the hospital worked. I knew what ward I was going on for IVs, I knew who to ring uhm, for appointments and if I had any problems, I could ring the CF nurses at the drop of a hat.

Karen also identified that not only was the inpatient system different, but that this also applied to outpatient clinics when she stated that, *"the whole appointment*

set up was different". Later in the interview, Karen makes a wider comparison when she suggested that *"there's a lot in adults that's completely different, not spoon fed any more"*, which suggests that she recognised the need to be more independent following transition.

Ben, in keeping with the rest of his interview, had little to say with regard to the changes between child and adult services, although he did identify some. Overall, Ben appeared to prefer adult services as he recognised that in children's services *"...there was no one of my age"*, which could imply that he felt lonely and isolated. Another important factor for Ben was increased freedom, and he explained that:

The adult ward is better. Like you get more freedom. Like you had your own room in both hospitals, but like, I don't know like, there is more freedom, like you could go wherever you want. Yeah, they let me leave whenever I want as long as I am back in time for my antibiotics and all the physio stuff that's fine.

Later in the interview, Ben returned to this theme when he identified that:

They were a bit stricter in [named DGH], cause like they wasn't too fussed on letting people out (pause) they preferred to keep them in. But with [named adult hospital] they are more laid back and you can like go wherever you want as long as you get your stuff done.

Although Ben views these examples as a difference between the two hospitals, this would also relate to age and the fact that individuals who attend adult services by definition are adults and as such they do have more freedom and choice than young people. The improved facilities within the adult setting were also important to Ben and he identified that: *"they've got like their own gym there and that's good"*. The emphasis Ben placed on the improved gym facilities could also relate to his general lifestyle, study commitments, and the type of course he was undertaking, as he was clearly a young man who was used to being active.

Molly appeared to have mixed feelings regarding the differences between child and adult services. In the first interview she referred to the issue of her mother being unable to stay with her on more than one occasion when she suggested that:

My mum stays with me so it's like for the two weeks when I go in, the difference like, she can't come in with me...'cause I'm used to her being there like 24/7.

This change in practice between services did not seem to be something that Molly had anticipated and the prospect of her mother not being able to stay appeared to be causing enough anxiety to overshadow the thought of transitioning to adult services.

Within the first interview Molly was also able to identify some positive aspects of moving to adult services as she saw it as “...*growing up and like there’s no children around and everything*” and it appears that at this point, in general, Molly saw this as a positive step forward.

However, by the time of the second interview, Molly had been admitted to adult services and the positivity seemed to have diminished. Molly identified that: “*I had an admission but I didn’t stay on the ward [CF unit] as it was full*”. Molly identified one major difference between child and adult services, particularly with regard to her admission for IV therapy:

With paed’s if they say two weeks, or they would say two to three weeks and they would let you out after ten days, which I think is not good. Because then when I found I was staying in for ten days, about two weeks later I had to go in again for more antibiotics. But with [named adult hospital] on the CF ward over there they said two weeks and they made sure you stayed in for the two weeks, which I know I wanted to come home, I so much wanted to come home but it was good because they stuck to that. It was two weeks and I stayed in for the two weeks and I had every single dose of that two weeks. Yeah it was really good.

Although she was reluctant to stay in hospital, making sure that she remained an inpatient for the full course of antibiotics was obviously important to Molly as she equated this to a reduced chance of being readmitted within a shorter period of time.

The changes Katie identified were predominantly positive, although Katie identified differences between child and adult services as well as changes she had seen occurring within adult services. As Katie was managed as a child at a DGH and not the children’s CF centre, her opinion was that, “*in a general centre [DGH] perhaps the CF management wasn’t as great, you definitely saw a difference in that*”. However, she then went on to suggest that:

When I was in the children’s centre, I could pop back every day even if I wasn’t staying in, whereas with the adult centre you’re kind of left to your own devices there with home IVs.

Although at this point she did not identify what they were, Katie started the conversation by suggesting that she had noted changes within the adult setting since her transition, but she then reverted to making comparisons between child and adult services.

Yeah, I think that with [named adult hospital] I've seen that change quite a lot since I started. But it was more specialised areas, because in the [children's] ward they were completely different. Uhm, separate rooms, family meeting rooms. I suppose in a general unit [DGH] you were always part of the hospital rather than the CF community if you like.

Again, within this theme, the participants were able to identify both positive and negative differences between child and adult services. In the main however, the participants tended to indicate more positive aspects and recognised that this was inevitable.

6.5.2: Managing Their Own Care

The majority of the participants identified that they were managing their own care in some way. However, in contrast to the other three participants, Molly did not really discuss any involvement in her own management during the interview as the main focus of her second interview related to one specific incident. However, Molly was managing her own care to a certain extent. This was identified in a discussion with Molly and her mother after the official interview had finished and consequently was not recorded.

Karen could actually identify the time when she was still in children's services and she decided to take control of her own management.

You know uhm (pause), they [the staff] wouldn't ask my mum how things were, they'd ask me and I was, you know, although I knew the answers, my mum always, kind of, chipped in and that was actually a turning point, where I actually said to mum, I want to go along to appointments on my own now.

Karen also recognised that although she was able to manage her own care at this point, her mother's continued attendance at outpatient clinics may have been influencing the way she was being approached by healthcare professionals. As she explains:

Yeah, you know, at home I was, I was always self-sufficient, but mum (pause) I don't think she meant to, but she really was involved in my hospital appointments and I think she sometimes forgot that I had a voice sometimes.

In relation to managing her own care Karen is clearly well versed on the expectations of this, as she identifies that:

I could reel off my medication any day now. I know what I'm on, what the dosage is and it's what's expected of you in adult. The doctor says, you know, what are you on, uhm, you know, what's the dosage of that and you know, they will trust you a lot more and they don't check back in the notes. They expect you to know, because you should know, you know, you take that medication every day and you should be in control of what you take.

Karen's ability to manage her own care is well defined and she is very clear that she should be in control of her own management and she uses the word 'control', which ultimately relates to the way she feels about managing her own care – that 'she' is in control of 'it'. This could be viewed in two different contexts; yes, Karen is in control of managing her own care, but to control something also means that you can regulate it, that you can influence it and by so doing, you have power over it. It is possible therefore, that in Karen's narrative, the use of the word control, is not only related to her self-management but that it is also relates to her concept of self-management in that it gives her some form of power over CF as a whole.

In contrast to Karen's responses, when asked about how he was able to manage his own care Ben identified that, "Yeah, with my college it's hard to do like my physio and stuff, it's hard to fit it all in". He then went onto explain that:

Like I'll do all my stuff now and again but like I won't do it as much as other people because like I am working as well, I go to work straight after college see... so it's hard. Yeah, it's hard to fit it all in, like I've barely got time but I do it when I've got time like I fit...(pause).

Ben's statement suggests that he finds it difficult to juggle his work and study commitments and still maintain his management regime. He identifies that self-management, or as he puts it, doing "all my stuff" is hard work. However, Ben also identified that he tries to maintain his management by linking this to his programme of study at college and the exercise he needs to do for this as he suggested that "I mainly just go to the gym, do stuff in college – like we are training almost every day and going to the gym in college".

The term self-management covers a variety of activities and Katie identifies how she undertakes her IV therapy at home on a regular basis. Katie's discussion regarding this was minimal and interrelated with her comment about support from

her parents as she identified that *“I’ve done home IVs where I can thanks to Mum and Dad”... “I do them myself, yeah... I’ve (pause) last couple of years it’s gotten more, it’s every 8-10 weeks on average”*.

The majority of the participants were able to articulate that they managed their own care at varying levels. This appeared to be a natural progression for all of them and something that they felt was necessary when they moved to adult services.

6.5.3: Relationships with Staff

Ensuring they had a good relationship with staff appeared to be important to all of the participants. Karen identified that, *“I think I had always appreciated how good my relationship was with all of the clinical team”* [in children’s services] and was concerned that this would still be possible in adult services.

It’s like anything, if you start a new job, or go somewhere new. You always worry, oh, gosh, am I going to have a good relationship with the people that I (pause) you know, probably will have to spend a bit of time with.

However, Karen did go onto identify that her concerns were not really justified:

Uhm, well just to say that as I’ve built a fantastic relationship with the paed’s team, I think I’ve built a fantastic relationship with the adult team. Uhm, it’s taken...it did take a little while, because you’ve got to get to know people and get to feel comfortable, but yeah, things have been ok with the adult team.

Ben also appeared to have formed good relationships with staff in both child and adult services:

Yeah, the doctors in the [named DGH] were nice, like they took care of me really well, but it’s the same in [named adult hospital] there’s still really good nurses there and they specialise in CF.

Molly’s perspective of the healthcare staff differed between the staff on the ward she was admitted to and the staff on the CF Team. Her initial comment again related to the fact that her mother was not able to be resident with her in adult services during her admission and the way in which the nurses provided her with different information:

Yeah, the nurses said, some nurses were like, 'Oh your mother can stay in with you', and I thought that's OK then other nurses said no [emphatically].

However, when discussing the CF team, Molly had a very different perspective as she suggested that, "the *CF team, I can't fault them they were amazing, they were really good*" and then went onto identify that:

Yeah, the CF team were brilliant, really, really good. With paedcs they only came around on the ward round, they wouldn't just come down to see if you were ok, you would only see them on the ward round. But over [named adult hospital] the CF team were there every single day.

It seems evident from these comments that Molly perceived that she received more support from the CF Team, than she did from the staff on the ward where she was admitted. Consequently, it appears that Molly felt able to build a better relationship with the CF team than the ward staff.

Katie only commented on staff within adult services and she appeared to be confident with the relationship she had built with them as she explains that:

Uhm, I just think that they seemed to be there for you [staff in adult setting] if there was any questions, any information you needed and again for a follow up.

In general therefore, the majority of participants felt that they were able to forge relationships with staff in the adult setting and that they could rely on them to provide support and information.

6.6: Superordinate Theme: Family Issues

All of the participants in this study recognised that their transition had also had some effect on their families. The main issues identified here were the feelings of the parents in relation to transition and the continued involvement of their parents in their care.

6.6.1: Parental Feelings

In varying degrees, all of the participants recognised that transition also impacted on their parents. Karen recognised that the transition process had been difficult for her mother to come to terms with and she suggested that it was:

Yeah, completely different, difficult. She was really upset, really, really, upset and I think she still finds it a bit weird that she doesn't come along to appointments with me now, because she wants to know the ins and outs. ... Uhm, it was really hard for her I think I think for the first year. Really kind of cut up about it, uhm, but she is used to it now.

As travel to the adult hospital was an issue for Ben, he also identified that this was somewhat of a problem for his mother also as he suggested that *"it's the same for my mum [travel] it's a bit of a pain for her like, but now I can drive, it's not so bad.* Ben also suggested that *"when I go in for two weeks, it's hard for her to come down. She's got two other kids.*

Likewise, Molly related her mother's feelings to her own concerns about her mother not being able to stay with her in hospital. As she suggests that *"Yeah, she's finding it strange you know when we move over and she can't stay there".*

In contrast, Katie was unsure of her parents' feelings regards her transition, although she identified that:

Uhm, they could see I was happy and comfortable, confident with the team, but yeah, I don't know how they felt about the fact that I was more independent.

Overall, the participants did not really provide a great deal of information about what they perceived to be their parents' feelings or concerns regarding the transition process and in the majority of interviews. Additionally, where family issues were mentioned, there was limited substance and depth to the discussion. However, all of the participants did raise some issues that suggested that the transition process did affect their parents in some way.

6.6.2: Continued Parental Involvement

All of the young people in this study recognised that their parents continued to have some involvement in their care in some way. Karen appears to imply that her mother's involvement was more her need than Karen's when she discussed this, but recognised that it was due to her being concerned:

Uhm (pause) and that wasn't because she was like a controlling mum. She was just worried I think. She just wanted to make sure that I was having the best level of care and that we were doing everything we could do to maintain my health.

Karen also identified that she kept her mother informed of changes in her care or management:

And you know, I keep her in the loop. If anything major or different happens, though.

Ben was less focused with his comments and did not actually mention his mother specifically, although it was assumed, given the context of the conversation within the interview, that he was discussing his mother. Ben suggested that, “we go down every month for an appointment” and that “...she still helps out”.

Molly related her mother’s continued involvement with her most recent admission to hospital and placed this within the context of ongoing support when she identified that:

She [mother] was leaving about half ten, eleven o’clock at night and coming in at seven o’clock in the morning and she did that for two weeks as well.

Katie was the most vocal in relation to parental involvement and divided this into current and previous involvement. Initially starting with the current involvement she stated that, “although even now aged 33 my parents are still involved quite a lot and that’s the way I want it”, She then went onto identify that “they’ve always helped me, it’s just made it easier for my adult life”.

Katie then went on to explain about the process for providing support that she had always experienced with her parents:

Uhm we (pause) the routine of the family, it was my dad that came to a lot of the clinics. Mum was involved and that (pause) something was going on for her but yeah, my dad was there and then mum obviously was supportive of (pause). She would have liked to have come, but she couldn’t at the time. But she was fully aware of everything going on and in touch with the hospital often.

Katie disclosed that the reason her mother did not take her to clinics was due to her own ill health at the time, but as this has no bearing on Katie’s actual transition, or the ongoing support her mother provided post transition, this will not be discussed further within this thesis.

6.7: Summary

To summarise this Chapter;

- The pre-transition information the participants received was variable, but visits to the adult setting were also identified under the umbrella of information.
- Comments regarding the actual transition process were limited, although participant comments were more positive than negative.
- There is evidence to suggest that transition did impact on the participants in this study, however, this may not have been recognised at the time.
- The participants were able to identify and clearly articulate the differences between child and adult services.
- The majority of participants were able to identify the way in which they managed their own care.
- Experiences of forming relationships with staff in the adult setting were varied.
- Participants were briefly able to identify that their transition had also impacted on their parents.
- All of the participants recognised and appreciated the continued involvement of their parents in their care.

6.8: Deviant or Negative Cases

It has already been established that within the analytical process of IPA, similarities within the participant stories are drawn together to form the superordinate themes. Smith et al. (2009) calls this recognition of patterns abstraction. In this study, the experiences of the participants were in the main, with slight variations, similar. However, it is also suggested that “oppositional relationships” (Smith et al. 2009 p97) or polarisations are examined. Molly’s transition experience stood apart from the rest of the participants in that she had an episode during her admission that was unique and had not at any point in time been experienced by any of the other young people. Therefore, this could be considered as a deviant or negative case (Pope et al. 2000). Pope et al. (2000)

suggest that deviant or negative cases are examples of discussions or experiences that are in opposition to the emerging hypothesis. Based on the evidence from the other young people who participated in this study, the emerging hypothesis was that overall, they had positive experiences. Molly's experience of the night visitor was unique in comparison to the experiences of the other young people. Consequently, it was considered to be a negative (polarised) case particularly as it clearly had a lasting effect on Molly and as such was included within this thesis.

In Molly's first interview, the main concern she identified regarding moving from child to adult services was the fact that her mother was unable to stay in residence with her when she was admitted. For Molly, this proved to be a justifiable concern and much of her second interview focused on what, prior to the commencement of the interview, we called her 'night visitor'. This 'naming' occurred prior to the interview and as a consequence 'off tape', when Molly asked me whether I had heard (from her mother) that she had had a visitor in the night, during her admission. During the brief conversation that ensued prior to the start of the interview, the 'visitor in the night' was shortened to the 'night visitor', so this is how he has been referred to throughout this thesis. It is evident that this situation had a considerable impact on Molly and as a consequence, regardless of how the topic was changed, the conversation always managed to revert back to the 'night visitor':

I went to [named ward]. I was so poorly, I had pneumonia and about 6 o'clock in the morning an old gentleman came [the night visitor] in (smiles and laughs). Naked! And he was just sat by my bed and he was smoothing my blanket saying you know, 'nice blanket' and stuff and I thought hmph! (blew lips out). And I couldn't move I was so poorly, I couldn't walk...and I had all my drips and that on one side and he was on the other side and there was no way I could move, so I had to press the cardiac arrest button and the nurse came in and she was like 'everything OK'? And I was like – I don't know this man and she was like 'oh come on move' [to the man]. But he came into my room three times and it was like, he escaped as well and it wasn't nice...seeing an old man, you know (pause) brought back by police...

Although she laughed and smiled throughout most of this narrative, Molly was clearly upset by this incident and was injecting humour perhaps in a vain attempt to make less of the situation. At the time, the only option available to Molly was to "press the cardiac arrest button". As Molly notes, this night visitation happened

on more than one occasion although when questioned she identified that this was not all on the same night:

No, different nights, but the first night he came in that's when he was naked and then smoothed my blanket and stuff and saying 'don't call the nurses'...obviously, I was going to call the nurses (laughs) and then, and then he came in, but the nurses took him straight back out because they seen him come from around the corner. But where we was, I don't know how he got past all the nurses to be fair, because there was the corridor and you had two sections...so I don't know how he got down there without any nurses seeing him. I understand he was ill and getting dementia and stuff and he didn't know he was doing but still (pause) he should have had one to one nursing you know what I mean?

It is evident from her narrative that Molly was still trying to come to terms with the incident of the 'night visitor'. Not only was she trying to make sense of how he made his way into her room without being seen, but Molly was also trying to justify that he did this because he had dementia and did not know what he was doing. As the majority of this second interview was taken up with the incident of the 'night visitor' it was evident that Molly had been badly upset by this incident and that this had had a lasting effect on her for the remainder of her admission. When I asked her how she felt about the incident she identified that:

Every little noise then, I just woke up and I just couldn't sleep for the two weeks because that happened at the beginning of my admission. I couldn't sleep, I just, I don't know, it just scared me I wanted to go home (laughs).

However, she kept reiterating similar points throughout her narrative.

Now I can laugh about it but at the time, I was so scared, really scared. At first I didn't realise that he wasn't dressed and when I turned the light on I was like oh no way! It's half five, six in the morning (pause) Mad!

Because, I don't know, I just, oh I don't know, I don't want to go in again in case it happened again. I don't think it would but you never know.

Yeah when one of the nurses walked in and I was like awake and it took me ages to get back to sleep and before I knew it, the cleaners were in my room and it was seven o'clock in the morning (laughs). I would sleep in the day because I was so poorly but oh (laughs) (pause – does not finish).

It is evident from these four statements interspaced throughout Molly's narrative that this incident altered her viewpoint of her move from child to adult services

and this has had the potential to alter her perception of any future admissions. Again, she laughs in several places in an attempt to make light of the situation, but on listening to the audiotape of the interview in conjunction with the transcript, the fear in her voice is evident.

This situation appeared to be compounded by the attitudes of the staff on the ward because when I asked Molly, 'what did the staff have to say about this?' Her response to this question was:

They didn't. They said uhm 'go and speak to him' and I said, 'it's no good speaking to him because he's got dementia and he's not going to remember going into my room not clothed, not fully dressed'. And they said like 'speak to his wife' and I said, his wife's like going to be shocked, I said, I don't want to put this on her as well. I said he's ill they don't need extra stuff on top of that. And then they were like 'oh OK then' and they didn't say anything else. They come into see if it was OK, like a few hours later and I was like – well no not really, I was shaken. And uhm, when it happened they took him out the room and didn't come back to see if I was OK, which I thought was a bit wrong.

This led me to question whether or not she thought that the 'night visitor' incident would have happened if her mother had been resident.

Oh I don't know (questioning tone). It's weird isn't it, I'm not too sure, it's hard to know. The toilets were right next to my room. It was my room and the toilet right next door and ... I thought he was looking for the toilet and I didn't think you know that he was coming in to see me... I said 'the toilets next door', and he said, 'I know', and I was like, 'Jesus, get out of my room', and he was like 'no' and I thought, 'oh I can't move' (half laughs). I was just too weak to do anything. And he shut the door really quiet, he was like 'shhh' and I was like oh! Yeah, closed the door and he was telling me to be quiet and then I said 'the nurses are coming', I thought that would make him go (half laughs) but it didn't and he was like 'no don't call the nurses, not the nurses', and I was like, the nurses are coming you had better go quick' (laughs).

This situation clearly had an effect on Molly as evidenced by the amount of time that she spent referring to it within the interview. As this incident occurred during her first admission following her transition, it also appears to have provided her with a somewhat negative opinion of adult services. Additionally this incident highlights the increased vulnerability of a young person who is already vulnerable due to her age and compromised health on a busy ward.

6.9: Reflection

Personally, I experienced a range of emotions when I undertook the interviews and listened to the audio tapes, which I did not really expect. For example, I was angered and disappointed that the nursing staff appeared to have failed Molly, both in relation to protecting her and also with regard to not following up the incident themselves. I also needed to keep reminding myself that I was a researcher and not a nurse during the interviews, but this was difficult at times.

However, more than anything else throughout all of the interviews, I was inspired by the 'matter of fact' approach the young people took to living with a chronic illness. It was what it was and they just made the most of it. Although they did complain about some issues, these were more of a systems problem (for example travel / facilities) they did not once complain about having CF and the issues that they were confronted with regarding that. This again highlights their courage, optimism and inspirational attitude towards life.

Chapter Seven

The Parents

7.0: Introduction

This chapter will provide a descriptive account of the experiences of the parents who participated in this study. As in the chapter describing the young people's experiences, the structure in this chapter is the same with a brief biographical description of each of the parents being provided prior to discussing their individual experiences. Then, in the same way as outlined with the young people in Chapter Six, the patterns and connections identified between the parents as a group will be described with the aim of presenting their shared experiences. Any quotes presented in this chapter are verbatim, this includes all pauses and paralanguage.

As identified in Chapter Six, pseudonyms are used to protect the confidentiality and anonymity of the parents (NMC 2015). This includes the name of Jenny's son (Tom) and Carol's other children, (Mike and Anna), when used within the verbatim quotes. Again, some information presented, is on occasion, deliberately vague to prevent identifying participants by job description or location of residency. Throughout this study the parental participants have been identified (in order of interview) as Jenny, Sally, Jeff and Carol. Matching the participants in the parental group to the young people in this study, is outlined in Table 6.

7.1: Idiographic Experience

Jenny

Jenny is in her forties and is separated from her husband. She has two children who are both in their early twenties and currently live at home with her. Jenny's son (Tom) who has CF (transitioned aged 18 years) and a daughter who does not have CF. Tom has only recently returned to live with his mother and sister, after living away from home for three years to study at university.

Of the mothers in the group, Jenny is the only one who regularly works outside the home as a registered nurse working within the adult setting. Jenny was also the only parent in the group who was not related to any of the younger participants. Initially Tom had agreed to participate in this study, but he withdrew his consent prior to being interviewed.

Jenny was very friendly and open but she was an interesting participant in that she appeared to be sending out mixed messages throughout the interview. She knew the system but she was not happy with Tom's medical / nursing staff or care. She missed him when he went to university but found it difficult when he was home; she found it hard not to be involved in his care but felt that it had been expected that she would return to the carer role when he returned home. It was difficult for me to determine whether this was her personality or whether it solely related to Tom and his return from university and the difficulties, she may have been experiencing around this.

Table 15: Preliminary Notes/ Themes - Jenny

Jenny's Comments	Preliminary Theme
And then just before he went over [named] the CF nurse from here [children's services] took him over there, well took us both over there.	Moving to adult services
...the CF nurses were brilliant! [named two CF nurses] were brilliant and they made it very smooth and the transitions clinics were good.	Nurses helped process
Mmm, yeah, we had a pack... It was a big pack... that they had lots of information leaflets in I'm sure they were given that same pack three times (laughs)...	Information
I mean looking back now I mean I still don't really know how it really works in [adult hospital]. They have different clinics on different days...But that hasn't really been explained to us.	Unsure of system
Yeah, I think it [transition process] was about over two years when he was 16-18.	Staggered process
Yes. I never really had a problem really...to me that's a natural thing [transition] a progression that should happen.	Not a problem
No I can't say it [transition] caused me any distress, not really.	Not distressed
When he went in and he was 18 he was on the CF unit, uhm whereas, this time he was on [alternate ward named] because they didn't have any CF beds.	Not on CF ward
So we never knew there was this, [alternative ward]...and it might have been nice to be told.	Lack of information
It's different...,it feels like, our experience has been that each consultant has got a different view and the treatment changes whichever consultant you are with, which we never had with paediatrics.	Inconsistency in management
Whereas we haven't had consistency at all.	Changing management
But I think looking back, the trouble was, because he didn't go [transition] until he literally had to go	Not sure of staff

to uni, they [the adult staff] didn't get to know him and he didn't get to know them.	
.. the nurses too in the adult service are lovely, they are just nowhere near as involved. And I don't feel like they know Tom.	Disengaged with adult staff
I don't know or whether it is that people don't really know him...they don't know his personality. But...they are nice (upbeat tone) (laughs).	Not known by staff
It's hard isn't it, ...you know they are looking after him and they are keeping a close eye and they are you know, having him back every week (pause) uhm and yes, he wouldn't phone them up for anything like we would phone [named CF paediatric nurse] up.	Disengaged with staff
And now that he's home he's dependant on me Because that's the way isn't it (shrugs)?	Mothers involvement again
And, it's only been now in the last couple of Months that I've started to go again [to clinic]. I've been a few times since he's been poorly because he's wanted me to go.	Mothers involvement
He asked me to go... he came home from one appointment and said 'mum they are just not listening to me'...So, I went with him and I know exactly what he means, this consultant was just (pause) very pleasant (smiles), but really didn't listen! Really (with emphasis) didn't listen to him...	Providing support
I left work early one day because it was the consultants round... and, Tom wanted me to be there and I, the overwhelming kind of feeling was you need to look after yourself better (stated in angry tone) and that was so unjustified.	Providing support
...you know healthcare doesn't faze me and if I am not happy with what service he was getting I know how to stand up and say it.	Advocacy
...it's a different physio, it's a different dietician. I am not sure how many dieticians they have up there mind, but you feel, his perception is, that he sees different people every time. Uhm, but that is just adult services (sounds fatalistic).	Inconsistency with staff
I went to his first appointment [adult clinic] and, and, he never wanted me to go again (said with some sadness).	Left out
This summer has been tough. I find it more difficult now (pause) but I am noticing it more now and actually I want to know more now, I am not really included. Because, because he's been ill, whereas when he actually transitioned he was well.	Feels left out
I've missed [named two CF nurses] desperately, desperately, but you know I see them around the hospital all the time [sounds wistful] and uhm, but it is strange, it is strange after being so involved in a service.	Sense of loss for children's nurses

And the nurses too in the adult service are lovely, they are just nowhere near as involved. And I don't feel like they know Tom I don't feel like they know him whereas, I guess he grew up with [named CF nurses] (pause) and they knew him so well, especially [named allocated CF nurse].	Differences between children's and adult nurses
But when he first went to uni I was proud of him (said with pride and forcefulness), I was so proud of him that he could do it all for himself.	Proud of achievement
...we've never let CF dominate us. We've always been very strong in that.	Being positive
So he never really became hospitalised, we were never a family that lived in the hospital and I think that makes a big difference...	Not hospitalised
We've done IV drugs everywhere...and yeah he has just carried on.	Being positive
...you don't realise how much, I hate to say it, but it's easier when he went away.	Guilt / wanting normality
You kind of get out of living with CF a little bit, of the roller coaster of it and then he'd come home and he'd be around and suddenly you'd be plummeted back into that roller coaster you had almost forgotten about.	Changes to family
Yes, and it has such a huge effect on the whole family...it's hugely time consuming, hugely and him being back has such a huge effect on me and my daughter, it really has.	Effect on family life

Working to the same format that I had used with the young people's transcripts, the preliminary notes enabled me to expand on the issues / topics with more extensive quotes from each of the parents. Therefore, starting with Jenny, the preliminary notes followed by more extensive quotes will be presented for each of the parents in the following section. This starts with Jenny's perception of the information she and Tom received prior to transition.

Mmm, yeah, we had a pack. I think I've still got it in the drawer. It was a big pack uhm that was in a folder that they had lots of information leaflets in. I'm sure they were given that same pack three times (laughs)...And it's the same sheet I use now for when I need to get in touch with them [CF unit]...Yeah, and at the time we were happy with the pack.

Jenny clearly found this information pack helpful although it appears that some additional information was required.

I mean looking back now I still don't really know how it really works [adult hospital]. They have different clinics on different days...but that hasn't really been explained to us.

Although Jenny does recognise that Tom may have received this information and that it may not have been relayed to her.

Uhm, but I don't know whether he was given the information and I am just not aware of it...who to kind of contact, what's the easiest way.

Jenny also viewed an accompanied visit to the adult setting and the first clinic appointment as a form of information that she found helpful.

And then, just before Tom went over [named] the CF nurse from here [children's services] took him over there [adult hospital]. Well took us both over there. And we had a visit and then I think [named CF nurse], who was his main CF nurse over here [children's services], came to his first adult appointment with us.

Yes (emphatically) the CF nurses were brilliant! [named two CF nurses] were brilliant and they made it very smooth and the transitions clinics were good.

With regard to the transition process itself, Jenny identified that it did not pose her any real concerns as she identifies that:

I never had a problem really...to me it's a natural thing [transition] a progression that should happen.

No I can't say it [transition] caused me any distress, not really.

Some of Jenny's concerns appeared to be caused by a lack of information and an understanding of the processes within the adult setting. This was particularly related to the alternate ward that appeared to be used when the CF unit was full.

When he went in and he was 18 he was on the CF unit, uhm whereas, this time he was on [alternate ward named] because they didn't have any CF beds.

So we never knew there was this [alternative ward]... and it might have been nice to have been told

Jenny's second point links to pre-transition information but also follows on from her previous comment as she identified that she was not aware that there was another area in the adult setting that managed individuals with CF. Although Jenny recognises that the CF unit is different within adult services, her main concern is inconsistency in care.

It's different..., there's a lot more CF nurses and there's (pause) it, it feels like, our experience has been that each consultant has got a different view and the treatment changes whichever consultant you are with, which we never had with paediatrics.

Whereas we haven't had consistency at all.

Another area of concern for Jenny was her perception that the adult staff did not know Tom as well as the nurses within children's services did and that because of this, it hampered his overall care.

But I think looking back, the trouble was, because he didn't go [transition] until he literally had to go to uni, [and left home] they [the adult staff] didn't get to know him and he didn't get to know them.

In the two statements below, she clearly equates this to their ability to care from him appropriately.

And the nurses too in the adult service are lovely, they are just nowhere near as involved. And I don't feel like they know Tom.

I don't know or whether it is that people don't really know him. I really don't know (pause) I, but they don't know him, they don't know his personality. But in saying that, they are nice (upbeat tone) (laughs).

In her next statement, Jenny again makes a comparison between care and 'being involved', going onto suggest that although the adult healthcare staff are "looking after" Tom, he has not been able to form a close enough relationship with them, for him to contact them if he needed to, as he would have with the staff in children's services.

It's hard isn't it, you know, I can't, you know they are looking after him and they are keeping a close eye and they are you know, having him back every week (pause) uhm and yes, he wouldn't phone them up for anything like we would phone [named CF children's nurse] up.

It is interesting that Jenny, as a registered nurse working within an adult setting, makes these observations about adult nurses. Here she clearly equates knowing her son well, with providing him with appropriate care and for her; it appears that it was only the children's nurses who could do this, as they were the people who knew him best. Jenny recognises that the adult nurses are not as involved with Tom as the nurses in children's services were and because of this, they do not know him as a person.

Although Jenny identified that Tom was able to care for himself when he moved out of home, she also recognised the rapidity of the default to family 'norms'

when Tom returned home, in that the expectation was that she took over the management of his care again. However, although this appeared to be something that Jenny had not anticipated, it is not clear on whose instigation this occurred.

And now that he's home he's dependent on me because that's the way isn't it (shrugs)?

Jenny also indicated that she at his request had started attending outpatient clinics again with her son and Jenny indicated that there was a specific reason for this:

And, it's only been now in the last couple of months that I've started to go again [to clinic]. I've been a few times since he's been poorly because he's wanted me to go.

He asked me to... he came home from one appointment and said 'mum they are just not listening to me'...

These comments lead onto the fact that there appeared to be times when Tom needed Jenny to speak up for him. Jenny describes two different situations the first where she accompanied Tom to an out-patients clinic and the second when she met with the doctor on the ward round when Tom was an in-patient.

He asked me to go... he came home from one appointment and said 'mum they are just not listening to me'...So, I went with him and I know exactly what he means, this consultant was just (pause) very pleasant (smiles), but really didn't listen! Really (with emphasis) didn't listen to him...

I left work early one day because it was the consultants round was coming around and I, he [Tom] wanted me to be there and I, the overwhelming kind of feeling was, you need to look after yourself better (stated in angry tone) and that was so unjustified you know.

Both of these examples identify two specific situations where Tom was not listened to by medical staff and as a consequence, he asked Jenny to intervene and support him. Although Jenny did acknowledge in her interview [not presented here] that Tom may not follow his management regime strictly at all times, she clearly takes exception to what she views as being an unjustified accusation.

This situation seems also to have affected the relationship between Jenny and the medical staff. In the first example, Jenny appears to be disgruntled with the situation but in the second example, she is annoyed by the way that Tom has been managed and the attitude of the medical staff towards him. Therefore, it is

possible that her trust in the adult medical staff and the tenuous relationship with them in comparison to the staff in children's services, has also been compromised. It was also apparent that Jenny had no concerns about speaking up and advocating for her son as she explains:

...you know, health care doesn't faze me and if I am not happy with the service he was getting I know how to stand up and say it.

Leading on from this Jenny also highlighted that there had been some inconsistencies in Tom's care particularly with regard to staffing as she identifies that:

...it's a different physio, it's a different dietician. I am not sure how many dieticians they have up there mind, but you feel, his perception is, that he sees different people every time. Uhm, but that is just adult services (sounds fatalistic).

Although Jenny recognised these inconsistencies of staff, she does so with a fatalistic attitude and suggested that this was what happened in adult services and there was nothing that could be done to change this.

Jenny also identified the point when Tom decided he wanted to visit outpatient clinic on his own:

I went to his first appointment [adult clinic] and, and, he never wanted me to go again (said with some sadness).

Added to this, Jenny also highlighted the difficulties she felt in trying to gain information and as she stated that she felt excluded, this could be taken to mean that she felt excluded from Tom's care.

This summer has been tough. I find it more difficult now (pause) but I am noticing it more now and actually I want to know more now, I am not really included. Because, because he's been ill, whereas when he actually transitioned he was well.

Jenny registered that her sense of loss also related to the fact that she missed the nursing staff within children's services. As she suggested that:

I've missed [named two CF nurses] desperately, desperately, but you know I see them around the hospital all the time [sounds wistful] and uhm, but it is strange, it is strange after being so involved in a service.

And the nurses too in the adult service are lovely, they are just nowhere near as involved. And I don't feel like they know Tom I don't

feel like they know him whereas, I guess he grew up with [named CF nurses] (pause) and they knew him so well, especially [named allocated CF nurse]

It is clear from this narrative that Jenny felt a keen sense of loss both in relation to being excluded from Tom's care as well as missing the relationship that she had clearly built up with the CF specialist nurses within children's services.

Despite this, Jenny identified the importance of remaining positive and not being overcome by CF or the 'system' as she describes her pride in Tom when he was able to leave home to attend university:

But when he first went to uni I was proud of him (said with pride and forcefulness), I was so proud of him that he could do it all for himself.

Jenny identified the importance of Tom being able to go away to university and recognises that it was the 'going away' that was more important, than the actual degree based on the fact that Tom was able to follow what was perceived to be a normal life pattern for many young people.

It is possible that Tom's apparent resilience and drive could have been instilled in him by his mother's attitude towards CF as Jenny suggests that

...we've never let CF dominate us. We've always been very strong in that.

Because of this, Jenny identified that Tom:

...never really became hospitalised, we were never a family that lived in the hospital and I think that makes a big difference...

Consequently, Jenny whilst recognised the importance of maintaining Tom's medication regime, she did not let it dominate the family and because of this she suggested that:

We've done IV drugs everywhere...and yeah he has just carried on.

Although Jenny maintains a positive attitude regarding Tom's ability to attend university, she did suggest that she found it very different when Tom left home. However, following a period of readjustment, it appears that Jenny and her daughter were able to settle down to a different form of 'family life', which changed again when Tom returned home:

...you don't realise how much, I hate to say it, but it's easier when he went away.

You kind of get out of living with CF a little bit, of the roller coaster of it and then he'd come home and he'd be around and suddenly you'd be plummeted back into that roller coaster you had almost forgotten about.

Yes, and it has such a huge effect on the whole family...it's hugely time consuming, hugely and him being back has such a huge effect on me and my daughter, it really has.

Although Jenny did not elaborate on the exact effect of Tom's return home, she evidently has mixed emotions regarding the situation. This demonstrates the impact that CF has on the family as a whole, both from an emotional aspect as well as the time factor involved in his management.

Sally

Sally is in her late-fifties and has been married to Jeff for 40 years, so forms part of the married couple within the parental group. With the exception of a two-year period, she has lived in the same regional area, close to an extended, supportive and close-knit family for all of her life. More recently, Sally has started her own business and has begun to work more outside the home, although she still prefers to work from home for the majority of the time.

Sally is a quietly spoken, articulate woman whose apparent confidence seems to contradict her past health condition. She is clearly knowledgeable regarding CF and all issues surrounding this and is involved quite heavily in fundraising for both the adult hospital and the CF Trust. She had very strong opinions with regard to staffing levels and the ability of nurses to care. A considerable focus of the interview was on her own experience of her daughter's (Katie's) diagnosis, which included a suggestion of having Munchausen Syndrome by Proxy and the subsequent development of agoraphobia. It was clear that this still caused Sally a considerable level of angst and she became very emotional during the interview although, on reviewing the transcripts, it was noted that despite bringing the conversation back to transition on several occasions, there was very little information disclosed regarding her daughter's health, management or transition. Although Sally's situation was interesting, it was not included, as it did not relate to the main question within this thesis.

Table 16: Preliminary Notes / Themes - Sally

Sally's Comments	Preliminary Theme
No not really, nothing written down.	Information
I've always been a hands on mum I haven't gone out to work in the hope to give her the best care possible and so yeah, yeah it [transition] was difficult.	Involvement
We knew she had the personality to go forward (pause) and yes it, it was almost like a redundancy [transition] especially because of my situation yeah.	Readiness
I think from a transition point of view (pause) especially from paed's, they did everything they could to get you ready for that change.	Getting ready
Uhm (long pause) hands up, it was more difficult for me [transition] because (pause) before she became 18, I myself became agoraphobic uhm (pause) so... I couldn't get out to the hospitals.	Problems because of own health
I couldn't live my life like that so I got some help and then I started [treatment]. So I was, that was good that I could be part of it.	Problems because of own health
Yes, that's my biggest concern [lack of facilities]...there's not enough beds, but also it's quite outdated.	Facilities
You know there's still uhm the sharing, mainly of bathrooms and toilet facilities...so it's pretty outdated.	Facilities
Uhm I don't think the communication is as good as it used to be.	Reduced communication
One time her husband to be, took her in because they were in [named area] and before he would let her go into the room [he] asked for cleaning things to go and clean it [the room] and that's not good is it?	Poor facilities
...some of the things that she's related back we can have a giggle about most of most of the time you know.	Positivity
...and I was accepted [by the staff] while I was there as well [adult services].	Relationship with adult staff
... he [GP] knew my situation knew how fearful it was for me that I couldn't get to the hospital, brought [to the house] and introduced him [the consultant] and that was all made quite easy for us.	Problems because of own health
... so yeah, thinking (pause) adult now what's going to happen uhm, but it was like going to a different little family and I think that was because it's a specialised unit.	Changing services
We've always had contact and if uhm perhaps if she's so poorly that she can't voice things herself that needs to be voiced, I will ask.	Speaking up
Uhm maybe that's because we make ourselves known. I don't mean that in an aggressive way	Speaking up

uhm and we are not pushy.	
There was one example where she said 'Mum, would you please'...that was when she asked me to speak out for her and uhm it was quite a surprise...	Advocacy
...and I very much knew that there was something not quite right and she was not being listened to... when she asked rather than me stepping in, that was about when she was 25 about 8 years ago.	Continued involvement
Yes, yes absolutely, she had never needed it [speaking up for her] before, never asked and it had to be done because uhm yes, let's just put it that way.	Advocacy
I know Katie and I know she could find her own way but the instinct of a mother is that you don't want them to do that [on their own] but we've always stepped back and we'll let her go forward.	Continued involvement
And when you see that one or two, well you know, probably one or two, a handful of the staff really, now are absolutely, well, one hopes that they are tired rather than complacent.	Changes in staff
The last two years there uhm the (pause) you know it sounds like I'm putting people down uhm, its changed – is that because of the pressure on them?	Changes in staff
And as I said, it was a family and yeah, it's a little family, the majority still are [nurses] but I think there are lots of weary people with the pressures that they have on them, put it that way.	Pressure on staff
...but only by a few, that has to be said and as I said before maybe it's just pure exhaustion too much asked of them I don't know I don't know (pause).	Pressure on staff
I felt redundant if I'm honest.	Sense of loss
Uhm because the diagnosis, you want to lock the door and keep everybody out and you know to (pause) to let them lead their own lives and you know you can't let them do that.	Sense of loss / grief
Katie lives her life to the full through all adversities and when she's well she's out there, and when she's not uhm (pause).	Trying to stay positive
[involvement of son-in-law] Yes, we talk openly and I said...if you will allow it uhm there's going to be much more involvement from Jeff and I in your marriage than perhaps there would be for others.	Continued parental involvement
I think we're lucky in as much as we are a family that can talk...	Being positive
...and when she has the IVs I go down a few days And cook up for them...	Continued parental involvement
...I don't know about acceptance [living with CF] you know, it's like a little knife going into you each time – it never gets any easier.	Ongoing effect of CF
Yes, we talk openly and I said [to son-in-law] 'do you know you're a great man' and he said 'what	Ongoing effect of CF

do you mean' and I said 'do you know (pause) if you will allow it uhm there's going to be much more involvement from [Jeff] and I in your marriage than perhaps there would be for others' and uhm he just put his arm around me and he said 'and I wouldn't expect it any different.'	
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Sally did not focus on the information they had been given before her daughter (Katie) transitioned to adult services as all she commented on was that they had received "...*nothing written down*". However, this could have been because a great deal of Sally's interview actually focused on herself and her own previous health issues.

Early in the interview, Sally identified that:

I've always been a hands on mum, I haven't gone out to work in the hope to give her the best care possible and so yeah, yeah, it [transition] was difficult.

However, this may not have been the only reason Sally did not go out to work, as in keeping with many other aspects of the interview, Sally also identified her own health issues when she discussed Katie's transition, which by definition would have made it difficult for her to leave the house.

Uhm, (long pause) hands up, it was more difficult for me [transition] because (pause) before she became 18, I myself became agoraphobic uhm (pause) so...I couldn't get out to the hospital.

Although Sally recognised that Katie may have been ready to transition, she used an interesting analogy (redundancy) to describe her own feelings about this.

We knew she had the personality to go forward (pause) and yes it, it was almost like a redundancy [transition] especially because of my situation, yeah.

As Sally's health had not allowed her to visit Katie in the children's setting, she was only able to comment on the differences she had witnessed since her daughter had been transitioned to the adult setting, much of which related to the facilities in the adult setting.

Yes, that's my biggest concern [lack of facilities]...there's not enough beds, but also it's quite outdated.

You know there's still uhm the sharing, mainly of bathrooms

and toilet facilities...so it's pretty outdated.

Sally also suggested that she believed that there was a reduction in communication between the staff and young people and their families as she identified that *"Uhm I don't think the communication is as good as it used to be"*.

Another area that Sally identified as being of concern was what she perceived to be the overall lack of cleanliness of the ward and highlighted a situation when Katie's husband took her to the hospital for an admission.

One time her husband to be, took her in because they were in [named area] and before he would let her go into the room [he] asked for cleaning things to go and clean it [the room] and that's not good is it?

However, Sally did try to remain positive and tried to make light of the situation.

...some of the things that she's [Katie] related back we can have a giggle about most of it most of the time you know.

Due to her health issues, Sally did not actually visit children's services when Katie was admitted as a child so, she did not appear to have formed a relationship with staff in children's services. Therefore, it is understandable that she provided limited comments regarding forming any relationship with staff in the adult setting as she identified that *...and I was accepted [by the staff] while I was there as well [adult services]*.

Because of Sally's specific health situation, it appears that some special arrangements were made for her and it is evident that any relationships with healthcare professionals within children's services could be defined as being outside the usual parameters.

Uhm you know we were, we were again if you like, not friends but acquainted with the consultant at [named DGH] because he took a huge interest, he, our GP, was a great friend of ours we had all been in school [together] he knew my situation knew how fearful it was for me that I couldn't get to the hospital, brought [to the house] and introduced him [the consultant] and that was all made quite easy for us that was fine so yeah, thinking (pause) adult now [following transition] what's going to happen uhm, but it was like going to a different little family and I think that was because it's a specialised unit.

The situation for Sally was different, and as she alludes to in her narrative, it appears that she did not really form a bond with the nursing staff in children's

services due to her inability to visit the hospital herself. However, living in a close-knit community, where the GP had been a friend since her school days, in conjunction with her health at the time, probably afforded her some dispensations, resulting in the consultant making domiciliary visits. Therefore, the bond that Sally formed was more aligned to the medical staff rather than other healthcare professionals and relationships with nursing staff were not formed until after Katie had transitioned to adult services.

Despite the length of time since Katie's transition, Sally identified situations where she needed to speak up as advocate for Katie, but that when this happens, she does so with the approval of Katie herself.

We've always had contact and if uhm perhaps if she's so poorly that she can't voice things herself that needs to be voiced, I will ask.

Sally suggests that the ability to do this is because they are able to approach the staff, within the adult setting.

Uhm maybe that's because we make ourselves known. I don't mean that in an aggressive way uhm and we are not pushy.

However, Sally also suggests that being known to staff, was sometimes not enough and identified a time when she needed to intervene on Katie's behalf as she identifies in the statements below.

There was one example where she said 'Mum, would you please'...that was when she asked me to speak out for her... and uhm it was quite a surprise...

...and I very much knew that there was something not quite right and she was not being listened to.

... she had never needed it [speaking up for her] before, never asked and it had to be done because uhm yes, let's just put it that way.

Sally does not disclose the actual situation that required her to speak up and advocate for Katie, but it is interesting to note that Katie was not an adolescent recently transitioned when this incident happened, but a young adult aged 25 years, who had already been managing her own care for some time.

Despite this, it is clear that Sally does recognise the need for young people to move forward and tries to enable this wherever possible:

I know Katie and I know she could find her own way but the instinct of a mother is that you don't want them to do that [on their own] but we've always stepped back and we'll let her go forward.

Although Sally appeared to have a good relationship with staff, she did suggest that she had noted changes in their attitudes during the time that Katie had been attending adult services.

And when you see that one or two, well you know, probably one or two, a handful of the staff really, now are absolutely, well, one hopes that they are tired rather than complacent.

The last two years there uhm the (pause) you know it sounds like I'm putting people down uhm, its changed – is that because of the pressure on them?

And as I said, it was a family and yeah, it's a little family, the majority still are [nurses] but I think there are lots of weary people with the pressures that they have on them, put it that way.

...but only by a few, that has to be said and as I said before maybe it's just pure exhaustion too much asked of them I don't know I don't know (pause).

Despite highlighting the issues of perceived complacency, Sally immediately counteracts this with suggesting that the reason for this is that they are tired, under pressure, exhausted and that “*too much [is] asked of them*”, and it is evident that she does not want to think badly of the staff, which again places the situation back onto the system and not the staff themselves.

Within her discussion, Sally also identified a feeling of loss related to her daughter's transition stating that, “*I felt redundant if I'm honest*”, which suggests that she felt that as she no longer had her daughter to care for, she had effectively lost her job. As with much of her interview, Sally turned her discussion back to the time of Katie's diagnosis and she also did this when discussing her feelings.

Uhm because the diagnosis, you want to lock the door and keep everybody out and you know to (pause) to let them lead their own lives and you know you can't let them do that.

Although this does not strictly relate to transition, it does identify the sense of loss that Sally felt when she received Katie's diagnosis and that it would appear that

at this point, Sally was already recognising the potential difficulties she would have with regard to letting Katie go when she was older.

This links to discussion surrounding continuing to be involved in Katie's care due to her diagnosis of CF. Sally suggested that this meant that she and her husband (Jeff) would need to remain involved in Katie's care and that she in particular had discussed this with her son in law.

Yes, we talk openly and I said...if you will allow it uhm there's going to be much more involvement from Jeff and I in your marriage than perhaps there would be for others.

In relation to how this evolved, Sally identified that "... when she has the IVs I go down a few days and cook up for them..." Sally also suggests that "*I think we're lucky in as much as we are a family that can talk...*" and she clearly feels that talking together as a family is important. Despite this, Sally intimates that there is no real acceptance to the diagnosis of CF as she suggests that:

...I don't know about acceptance [living with CF] you know, it's like a little knife going into you each time – it never gets any easier.

Jeff

Jeff is also in his late-fifties, is married to Sally and is the father of Katie, who is an only child. Like Sally, Jeff grew up in the same regional area and has lived there for the majority of his life. From choice, Jeff works full time in the town where he resides with his wife. His occupation has always allowed him to be flexible and this has enabled him to participate in his daughter's care when she was a child. Due to Sally's agoraphobia and her inability to leave the family home for many years, Jeff became the main carer for his daughter outside the home. This meant that he would take Katie to hospital for all her out patient appointments and stay with her as a resident parent when she was admitted into hospital. Jeff is an active fundraiser within the CF community and has undertaken several 'adventure sports' sessions with his daughter to raise funds.

Jeff appears to be a pragmatic individual but he also seems to take a philosophical viewpoint on life. During the interview it was clear that he thinks before he speaks and some (but not all) of his responses were measured. He seems to be optimistic and tries to focus on the positive aspects of improved management in CF, although it becomes evident that at times his optimism waivers.

Table 17: Preliminary Notes / Themes - Jeff

Jeff's Comments	Preliminary Themes
I don't think we were given a lot of information and uhm, from memory... I don't think there was anything ever written, or any presentation or anything like that.	Pre transition information
So it was all a little bit of a (pause) of memory, really a little bit of an unknown quantity, So I suppose uhm if there was a piece of information a pamphlet or brochure or whatever, uhm saying how long it [ward in adult hospital] had been going...and the treatment itself, I suppose it might have been helpful in some way. I think, you know, we got used to things as we went along really.	Lack of information
Uhm, well the main things that come to mind really, is that the transition age is pretty much a funny age for some ... they are wanting to be adults but at the same time uhm, don't want to leave things that they get used to.	Readiness
...if I remember rightly, she did the transition slightly after she was 18.	Timing of transition
...we knew that she was outgrowing the paediatric unit not so much in terms of age, but uhm, but in the fact that their knowledge of the condition wasn't as great as it was in [adult hospital].	Readiness
Uhm and I think initially, we were perhaps a little bit reluctant to do it [transition].	Readiness
Uhm, but you know at the end of the day that, that was the best thing for her [to transition].	Good to move
I think that she took to it reasonably well, as well as anybody could anyway and adapted to it.	Perception of daughters transition
You know I had to take her there [to adult hospital] and leave her there. Because you know, I had never done that before.	Change in situation
So going to [adult hospital] the first time if you like, it was all a new thing and a learning experience really.	Differences in services
...you tend to, you adapt to new things as you find them.	Adapting to change
There are occasions where the ward is full anyway uhm and she just goes home then [to manage her own IV therapy].	Differences in services
...she doesn't actually spend much time on the CF unit anyway because a lot of the time she does her own antibiotics at home.	Differences in services
[when Katie went to university] then we found that our sort of grasp on her treatment and our supervision was slowly starting to slip away.	Loss of control
So now really our involvement isn't as great as it should be really...and you almost missed the routine that we had with her...ideally would like her to come home at least for a few days. Just too sort of get her feet on the ground again...	Wanting to be involved

We'd be here [at home] at 9/10 o'clock when we should have been doing it [physiotherapy] looking at each other and wondering what do we do now type of thing.	Extra time
...obviously as a parent you feel it's your job to be looking after her.	Wanting to be involved
...even now...if she's not well she, (pause) we particularly would like her to come home at least for a few days.	Wanting to be involved
Uhm (thinking and apparently choosing words carefully) our feeling is that uhm, that as time has gone on, there's less, she's getting perhaps less, much less and less attention. And that's not a criticism of the staff over the unit or anything.	Changes with staff
But the numbers of staff hasn't increased on the ward...and uhm (pause) our impression at as a result of that uhm, that things have started to slide a little bit.	Changes with staff
Again, it's not a criticism of anybody in particular it's just, it's just a numbers situation I would have thought – yeah it is.	Systems issue
It's a shame really because it's not a nice illness to have and you need all the support and back up you can get and sometimes it isn't there...	Lack of support
But it is frustrating you know, you want to be able to do something but you don't know quite what – other than raising a couple of hundred quid here and a couple of hundred quid there...	Trying to make a difference
I think Katie in actual fact was taken away from us if you like as much as her having to travel to [named adult hospital] and have these things [management] done.	Loss of control
It was just a case of playing with the cards you were dealt I guess (laughs).	Being positive
So when it came [diagnosis], it was a surprise as I say and then we did everything, we adapted to it fairly quickly and did what we could, and hopefully done a decent job.	Being positive
We've always tried to instil in her to look after herself because things will get better and hopefully we are getting to that point.	Keeping a positive outlook
I wasn't prepared for it [diagnosis]. Although even if you are prepared, I don't think it helps...but it did, it shook me.	Impact on self
I don't know whether there's any stats on it but I would imagine there's been quite a number of divorces when CF is involved.	Impact on family
The one thing we did decide that with Katie having CF, we decided not to have any more children because of that.	Impact on family

At the start of his interview Jeff identified that he had been provided with very little information prior to his daughter's transition:

I don't think we were given a lot of information and uhm, from memory... I don't think there was anything ever written, or any presentation or anything like that.

He also identified that some practical information regarding the adult setting would have been useful:

So it was all a little bit of a, (pause) of memory, really a little bit of an unknown quantity. So I suppose uhm if there was a piece of information, a pamphlet or brochure or whatever, uhm saying how long it [ward in adult hospital] had been going on, how, when they got there and the treatment itself, I suppose it might have been helpful in some way. I think, you know, we got used to things as we went along really.

Jeff recognised the inevitability of transition and that the adult hospital provided more specialist CF management than the DGH she was attending:

... we knew that she was outgrowing the paediatric unit, not so much in terms of age, but uhm, but in the fact that their knowledge of the condition wasn't as great as it was in [adult hospital]

Uhm, but you know at the end of the day that was the best thing for her [transition]

Jeff included his perception of his daughter's perspective of transition when he suggested that:

I think she took to it reasonably well, as well as anybody could anyway and adapted to it.

As Jeff was the parent who was resident with Katie during her admission to children's services, it is perhaps understandable that he seemed to find not staying with Katie in the adult setting difficult:

You know I had to take her there [to adult hospital] and leave her there. Because you know, I had never done that before.

So going to [adult hospital] the first time if you like, it was all a new thing and a learning experience really.

However, Jeff accepted this in his usual pragmatic way as he suggested that "...you tend to, you adapt to new things as you find them".

Indirectly, Jeff also mentioned the perceived shortage of beds on the CF ward as he identified that:

There are occasions where the ward is full anyway uhm and she just goes home then [to manage her own IV therapy].

After being so involved in his daughters care Jeff seemed to have some difficulty in not being able to participate in Katie's care as she got older as he suggests that:

[when Katie went to university] then we found that our sort of grasp on her treatment and our supervision was slowly starting to slip away.

So now really our involvement isn't as great as it should be really...and you almost missed the routine that we had with her...ideally would like her to come home at least for a few days. Just to sort of get her feet on the ground again...

He then suggests that, "...obviously as a parent you feel it's your job to be looking after her". These comments are interesting given that Katie is married and lives with her husband in an area that is closer to the adult CF hospital than her parental home. Consequently, it appears that Jeff is inferring that she would be better off 'at home' (parental) than being cared for by her husband.

However, Jeff also recognises the time factor involved in caring for someone with CF and suggests that since Katie has moved out and they are not participating in her care, both he and Sally find it difficult to know what to do with their 'spare' time.

We'd be here [at home] at 9/10 o'clock when we should have been doing it [physiotherapy] looking at each other and wondering what do we do now type of thing.

At certain points in Jeff's narrative, he linked his comments with wider issues within the healthcare system such as staffing numbers on the CF unit and followed on from this with his belief that Katie was having less attention from staff on the unit than she had previously received.

Uhm (thinking and apparently choosing words carefully) our feeling is that uhm, that as time has gone on, there's less, she's getting perhaps less, much less and less attention. And that's not a criticism of the staff over the unit or anything.

Jeff suggests that this lack of attention relates to staffing issues and infers that if staffing issues were different, situations related to care would not be (in his opinion) deteriorating.

But the numbers of staff hasn't increased on the ward...and uhm (pause) our impression is as a result of that uhm, that things have started to slide a little bit.

Again, it's not a criticism of anybody in particular it's just, it's just a numbers situation I would have thought – yeah it is.

As Jeff is an active fundraiser for the CF Trust and the CF hospital, it is perhaps understandable that he relates the situation he is discussing to the condition of CF itself and a perceived lack of support for individuals with this condition.

It's a shame really because it's not a nice illness to have and you need all the support and back up you can get and sometimes it isn't there...

Jeff also identifies the frustration he feels in relation to fundraising and a perceived lack of improvements for individuals with CF, as he identifies that:

But it is frustrating you know, you want to be able to do something but you don't know quite what – other than raising a couple of hundred quid here and a couple of hundred quid there...

With regard to his own feelings, Jeff clearly equates the transition process to 'losing' Katie altogether. As he explains:

I think Katie in actual fact was taken away from us if you like as much as her having to travel to [named adult hospital] and have these things [management] done.

It is clear from this statement that Jeff believes that Katie's transition to adult services was the catalyst for his reducing input into her management and care and he appeared to be a little resentful of this. However, Katie transitioned close to the time she moved out of home to attend university, so it is interesting that Jeff equates transition alone to his sense of loss.

However, Jeff remains pragmatic in his approach to CF as a whole and suggests that when he received the news of Katie's diagnosis that:

It was just a case of playing with the cards you were dealt I guess (laughs).

So when it came [diagnosis], it was a surprise as I say and then we did everything, we adapted to it fairly quickly and did what we could, and hopefully done a decent job.

Clearly Jeff has tried to instil a sense of optimism in his daughter to ensure that she remains relatively well until improvements in management occur.

We've always tried to instil in her to look after herself because things will get better and hopefully we are getting to that point.

Despite this, Jeff also recognises that Katie's diagnosis had had a considerable impact on him and he identifies that:

I wasn't prepared for it [diagnosis]. Although even if you are prepared, I don't think it helps...but it did, it shook me.

Following on from this, Jeff also identifies that having a child with CF has the potential to place a strain on a marriage and although Jeff had informed me that he had been married to Sally for 40 years, and did not relate this to his own marital relationship specifically, it appeared that he had considered the strain CF placed on parental relationships:

I don't know whether there's any stats on it but I would imagine there's been quite a number of divorces when CF is involved...

However, coupled with Sally's agoraphobia, the strain on his marriage could have been considerable and Jeff also identified that Katie's diagnosis of CF had influenced their decision not to extend their family.

The one thing we did decide that with Katie having CF, we decided not to have any more children because of that.

This may or may not have been a difficult decision for Jeff and Sally, but the impression I gained was that although Jeff felt this to be the 'right' decision, it had also been a very sad decision.

Carol

Carol is in her forties and has been divorced from her husband for some time. She has three children, an older son (20 years) a daughter (Molly 18 years) and a younger daughter (10 years) all three still maintain regular contact with their father. Within this family, it is only Molly, the middle child, who has CF.

Carol has a lively personality and it was not difficult to match her as Molly's mother. She was 'down to earth', forthright and had no difficulty in speaking her mind. The interview took place in her home and I found her to be kind and welcoming. I had met Carol previously when I interviewed Molly and it was after

speaking with Carol on the first occasion that I decided to seek ethical approval to include parents in this study.

Carol does not work outside the home and it is clear that her children are a very important aspect of her life. She has been heavily involved in Molly's CF management from the outset, supported in this by both of her parents who live nearby. Carol is also a vocal campaigner regarding the needs of individuals with CF, particularly in relation to funding and new forms of medication and she has been instrumental in securing the use of the drug Kalydeco® for children and young people within this part of the UK.

Table 18: Preliminary Notes / Themes - Carol

Carol's Comments	Preliminary Themes
When we had to go over we did have some paperwork with uhm, just like the phone numbers and uhm stuff about who's who and that was about it really, (pause) yeah.	Information
I can't fault the CF team because they were really good but I just don't think they give enough information out of going over from paed's to adults.	Lack of information
Uhm, they took us over once. Uhm we had a little look around at outpatients. Uhm met a few of the nurses that were there.... Uhm looked around the ward once...	Pre transition visit
So we knew we were building up to going over [transition] but it was more just saying 'right you're going over' nothing really introducing us to much to it.	Lack of information
Yeah, it was a big step [transition].	Making the move
Uhm, it's a big step, it's hard, it's like going from junior school to comprehensive school really (pause). It is that big step for them.	Impact of transition
a difficult part for me was taking Molly over and leaving here there.	Own feelings about transition
Uhm, you're not allowed to stay in overnight with them and I know that they are getting older but still, they may like their parents to stay.	Differences in services
The CF team [adult] was absolutely fantastic they were on the ball.	Perception of good care
The nurses [ward nurses] were good [said with some trepidation]. One nurse did give her too much medication...so that was a bit (pause) a big eye opener.	Medication error
Every time they were putting Molly's medication in the pot we were going through them to make sure [they were correct] Never had that problem before [in	Insecure / not able to trust

children's services].	
Yes, we had to ask for her nebs... We'd ask for them and sometimes like an hour or so later they still wasn't there, so we had to go and ask again.	Delayed medication
Uhm, quite a few times we've found tablets on the floor in her room where they dropped her tablets and hadn't picked them up.	Medication issues
Uhm, it's, yeah. I don't know if it's because she wasn't on the CF ward. I think if she was on the CF ward it would be a bit different.	Differences in care
The nursing staff I think opened our eyes a little bit. Not the CF nurses, the nurses on the ward. The CF nurses were amazing, absolutely amazing, I couldn't fault them in one way, in any way at all.	Differences in nursing staff
I had to ask for her Kalydeco® medication a few times, that's the super drug she's on.	Delayed medication causing anxiety
Uhm, sterilisation with her port, I didn't think that was as good over the adults.	Differences in services
It's totally different, totally different from paediatrics.	Difference in services
Physio's changed slightly as well...	Differences in services
Now Molly's gone over to [adult hospital] (pause) uhm, she's started speaking to a few CFs [other patients] and...I think it's opened Molly's eyes a bit more.	Mixing with other patients
Uhm (pause) but yeah, they do mix [in adult hospital] and they are not supposed to.	Mixing with other patients
I know quite a few people in [named adult hospital] said to Molly 'oh we do mix, we're not supposed to but we do mix, they [the staff] don't like it, we get told off'. But they do, they go out in the car and that together.	Mixing with other patients
Even if they got busy you never had to ask for anything ever in paed.	Differences in services
Uhm, it's not knowing any of the nurses.	Relationship with staff
Uhm, she's a bit needle phobic as well. Uhm so they [staff in adult setting] were just coming in her room with a needle and saying 'right I'm just going to do you bloods'	Not being known by staff
They were very friendly over there in [adult hospital] but we don't know them like we've, like with paed.	Relationship with staff
So first thing in the morning and late at night [arrive and leave] but it was hard. I think (pause), I didn't sleep much [at home] to be honest because I was just waiting for the phone to ring (laughs). Uhm, which it did once when Molly had that gentleman come into her room.	Maintaining involvement
I've got to learn to back away a bit really,	Letting go

which is, I find hard because she's still my baby if you understand (laughs).	
Cause I've done it for like 18 years and it's so hard now [not to do it].	Letting go
[regarding stepping back] I struggle with it to be honest with you. I keep it to myself...	Letting go
Oh, (pause) it was scary to know, I'm thinking she was in hospital safe, she was safe, he wasn't doing no harm, it's just he didn't know where he was and to be fair to the nurses, they are busy and I understand that they can't watch him 24/7. [related to intruder in daughters room]	Staffing issues
You know over there in adults they were absolutely rushed off their feet and you had this wanderer as well going around and it was like, it was frustrating for us because we had to ask for the medication...whereas before [children's services] we always had them in our fridge and we could do them as and when.	Staffing issues
No, I just, I've just got to try and let go.	Letting go
You know it's like, I've got so much more Time on my hands. I'm thinking what can I do to keep busy?	Reducing involvement
Before she was on that [Kalydeco®] I constantly worried about the future, really, really scared of the future	Trying to be optimistic
But, there is always that little doubt, thinking of it [Kalydeco®], does it work, will it work, will it work forever? Uhm (pause), so yeah, I am scared of the future.	Own fears
They [other children] would have to go down my mum's for two weeks [when Molly was admitted].	Caring for other children
I'm probably a nag to her (laughs)...	Involvement in care
I found it hard trying to split myself three ways... trying to make sure that the other two were alright as well...	Pressure on self

Carol's interview provided a considerable amount of information regarding a range of topics, starting with the information provided prior to her daughter making the transition from child to adult services.

When we had to go [transition] over we did have some paperwork with uhm, just like the phone numbers and uhm stuff about who's who and that was about it really (pause) yeah.

Carol also accepted that a visit to adult services constituted part of the information she received.

Uhm, they took us over once. Uhm we had a little look around at outpatients. Uhm met a few of the nurses that were there.... Uhm looked around the ward once... Uhm [named], Molly's CF nurse from the paediatric unit, she was fantastic (pause). Uhm, (pause) she done (pause) like she came over and met us over there [adult hospital] with them [adult staff].

However, Carol did become a little contradictory with regard to the perceived support from the CF team in children's services and the information they provided prior to transition, as she explains:

I can't fault the CF team because they were really good but I just don't think they give enough information out of going over from paed's to adults

So we knew we were building up to going over [transition] but it was more just saying 'right you're going over' nothing really introducing us too much to it.

Carol also discussed being ready for transition from the perspective of herself and her daughter Molly. Firstly, she identified that, "Yeah, it was a big step" and then went onto identify that:

Uhm, it's a big step, it's hard, it's like going from junior school to comprehensive school really (pause). It's a big step for them.

Earlier on in this chapter I described Carol as being a vocal campaigner with regard to the services provided for children and young people with CF. It is not surprising therefore, that she had the most to say with regard to management and the changes in practice between child and adult services. Additionally, as Molly was the last of the four young people to transition and had only recently had an admission to adult services, these experiences were fresh in Carol's mind and she was able to (and did) make comparisons with children's services.

Although it was her first admission to adult services, Molly was not admitted to the CF unit due to lack of beds. This was reflected in Carol's comments as within her discussion she makes a distinction between the CF nurses and the alternative ward nurses. One of Carol's main concerns was that she was unable to stay with Molly when she was admitted to adult services and she explains that:

A difficult part for me was taking Molly over and leaving her there. Uhm, you're not allowed to stay in overnight with them and I know that they are getting older but still, they may like their parents to stay.

Carol then makes a distinction between the CF team and the ward staff when she suggests that: *“the CF team was absolutely fantastic they were on the ball”*.

However, she did not appear to have the same opinion of the ward nurses although Carol did try to keep a positive attitude to their care by identifying that they were “good”.

The nurses [ward nurses] were good [said with some trepidation]. One nurse did give her too much medication...so that was a bit (pause) a big eye opener.

The administration of incorrect medication clearly put Carol on alert and led to a number of comments within the interview regarding medication issues.

Every time they were putting Molly’s medication in the pot we were going through them to make sure [they were correct]. Never had that problem before [in children’s services].

Carol identified that there were also delays in Molly receiving her nebulised medication, which caused her some concern, particularly as she suggested that there is a routine to taking these. However, she did seem to attribute this to the fact that Molly was not on a CF ward.

Yes, we had to ask for her nebs. Uhm (pause) I think it wasn’t a CF ward, I think if she was up on the CF ward it would have been totally different. I think they’ve probably got their times haven’t they [for medications] and I understand, like it was a big ward and they had so much patients to look after. But with her nebs, you’ve got, she’s in such a routine. We’d ask for them and sometimes like an hour or so later they still wasn’t there, so we had to go and ask again.

Carol again makes a distinction between the CF team and the ward staff and suggests that Molly’s care may have been different if she had been admitted to the CF ward:

Uhm, it’s, yeah. I don’t know if it’s because she wasn’t on the CF ward. I think if she was on the CF ward it would be a bit different. The CF team were I think spot on they were fantastic they couldn’t do enough. Uhm, if we asked [the CF team] for anything like a letter for her college they were there (snaps fingers) next day – done and all typed up. They were fantastic. So I do think the CF team care wise, were amazing. The nursing staff [ward staff] I think opened our eyes a little bit. Not the CF nurses, the nurses on the ward. The CF nurses were amazing, absolutely amazing, I couldn’t fault them in one way, in any way at all.

Carol's perception of the contrast in care between the nurses is obvious, and she demonstrates this in the way she divides them into two distinct groups, CF nurses and ward nurses, with the CF team providing what she perceived to be appropriate care and the care provided by the ward staff less so.

In relation to drug management and administration, Carol also identified that tablets had been left on the floor:

Uhm, quite a few times we've found tablets on the floor in her room where they dropped her tablets and hadn't picked them up.

Kalydeco® is a recently developed medication prescribed for individuals with CF, and both Carol and Molly informed me in their individual interviews, that whereas prior to commencing Kalydeco® Molly had been admitted to hospital 'every few months', since taking Kalydeco®, Molly had only had one admission in 19 months, which had been for pneumonia and was not CF related. It is understandable therefore, that Carol considers Kalydeco® a "super drug" and is concerned about the consequences if this medication is administered late, or overlooked.

I had to ask for her Kalydeco® medication a few times, that's the super drug she's on.

Carol identified that medication administration was not the only difference she experienced as she identified that this also related to the care of Molly's Portacath and physiotherapy:

Uhm, sterilisation with her port [Portacath], I didn't think that was as good over the adults.

Physio's changed slightly as well (pause thinking). Physio's are fantastic over there, yeah, physio's I think they are more like, IF [you want to do physio]. Like over paediatrics with the physio's, they (pause) you do your physio, that is it (with emphasis). Over the adults, 'do you want to do physio today?' It's not 'you're doing physio' (with emphasis). And...when Molly was really unwell... she was just like 'oh just do my Accapella' or something, whereas they should be in there doing it, trying to shift that pneumonia out. I've done it myself, uhm (pause) it's (pause) yeah, I think they need to be more stricter with the physio side of it, because IF, you want to do it, you know teenagers, do they really want to do physio? It's only that I was there that I was like, 'right physio' (laughing). You know if they can lay in bed all day, they will lay in bed. Uhm (pause) I think that's, I wish they were more stricter on that. If I wasn't around I just think... (trails off).

In this part of Carol's narrative, she seems to be trying to come to terms with the lack of emphasis placed on actually *doing* physiotherapy as opposed to only *suggesting* that physiotherapy should take place. Again, comparisons are made between child and adult services and she even makes comparisons with her own care, in other words, if she can instigate physiotherapy when Molly is unwell, then the staff should also be able to do this, which appears to be a reasonable assumption.

Carol then made a few generalised statements throughout her interview that draw together her overall opinion of adult services:

It's totally different, totally different from paediatrics.

That was a huge difference to be honest

Even if they got busy you never had to ask for anything ever in paed.

Another final difference that Carol highlighted was that there were less restrictions on the socialisation of individuals with CF in adult services and that as a consequence of this, Molly had come into contact with other people who had CF:

Now Molly's gone over to [adult hospital] (pause) uhm, she's started speaking to a few CFs [other patients] and...I think it's opened Molly's eyes a bit more.

Uhm (pause) but yeah, they do mix [in adult hospital] and they are not supposed to.

In the first statement, Carol appears to be suggesting that since her admission to adult services, Molly is able to meet with individuals who have CF, who may be at a more advanced stage of the disease, which Molly had not previously encountered. In the second statement, Carol also recognises that within adult services, there is a greater opportunity for individuals with CF to mingle with each other and as she highlights, this is generally discouraged.

7.2: Summary

This section has identified the individual experiences of the parents within this study. However, when working through these individual themes it became apparent that some patterns were emerging. In the next section and in keeping with the IPA process, the participants shared experiences (convergences) will be drawn together. Although an experience that could be considered as unique

(polarisation) within Sally's interview was noted and was going to be used as a 'deviant / negative case', on re-reading the transcript, listening to the audio recording again and reflecting on this, it was determined that although interesting, it only related to Sally's experience of Katie's diagnosis and not transition, so it was omitted. Consequently, there is no 'deviant / negative case' identified within the experiences of the parents.

7.3: Parents: Shared Experiences

Although the initial aim of this study was only to undertake research with young people, the data generated from the parental interviews provided a greater level of depth and richness of data than that generated from the young people's interviews. This provided an added dimension to the results that would not have occurred without the inclusion of parents within this study.

The parents who participated in this study were all in their forties or fifties, and comprised of two single parents (one separated and one divorced) and one married couple. Only one of the three mothers (Jenny) worked outside the home on a regular basis, and the only father in the study (Jeff) worked close to his home setting. Three of the parents were related to the young people in this study. Only one of the mothers in the study had a son who had declined to be interviewed.

Again in keeping with the IPA process and following the same format as set out in Chapter Six, the preliminary themes from the individual transcripts were drawn together to form the subordinate themes and this process is outlined in the table below.

Table 19: Drawing Together of Preliminary Themes - Parents

Participant Comments	Preliminary Theme
Information / staggered process / unsure of system / lack of information / pre transition information / pre-transition visit	Pre Transition information / preparation
Readiness / getting ready / not a problem / not distressed / timing of transition / good to move / perception of daughters transition / making the move / impact of transition / own feelings about transition	Readiness for transition
Not on CF ward/ inconsistencies in	Comparisons in service

management / changing management / facilities / poor facilities / changing services / change in situation / differences in services / adapting to change / perceptions of good care / medication error / delayed medication / medication issues / differences in care / delayed medication causing anxiety / mixing with other patients	
Not sure of staff / disengaging with adult staff / not known by staff / relationships with adult staff / changes in staff / Insecure and unable to trust / differences in nursing staff / relationships with staff	Forming relationships with staff in the adult setting
Inconsistencies with staff / differences between children's and adult staff / reduced communication / pressures on staff / changes in staff / systems issues / staffing issues	Staffing Issues
Left out / feels left out / sense of loss for children's nurses / sense of loss / sense of loss and grief / loss of control / extra time on hands /	Sense of loss
Mothers involvement / providing support / advocacy / proud of achievements / being positive / not hospitalised / involvement / positivity / continued involvement / speaking up / trying to stay positive / continued parental involvement / wanting to be involved / trying to make a difference / being positive / keeping a positive outlook / maintaining involvement / letting go / reducing involvement / trying to be optimistic / involvement in care	On-going support and advocacy
Changes to family / effect on family life / guilt wanting normality / problems because of own health / ongoing effects of CF / impact on self / impact on family / own fears / caring for other children / pressure on self	Effects of CF on family

As identified in Table 20, all the participants commented on all of the issues that were grouped together initially into preliminary and then into subordinate themes.

Table 20: Cross Referencing Preliminary Themes - Parents

Preliminary Themes	Jenny	Sally	Jeff	Carol
Pre Transition information	X	X	X	X
Readiness for transition	X	X	X	X
Comparisons in service	X	X	X	X
Forming relationships with staff in the adult setting	X	X	X	X
Staffing issues	X	X	X	X
Sense of loss	X	X	X	X
On-going support and advocacy: stepping up and stepping back	X	X	X	X
Effects of CF on the family	X	X	X	X

Following the development of the preliminary themes, three overarching superordinate themes were identified; Transition, Contexts of Care and Family Issues. These then led to the development of the subordinate themes, and the way in which these sit within the superordinate themes are set out in Table 21.

Table 21: Ordering of Themes - Parents

Superordinate Themes	Subordinate Theme
The Transition Process	Pre - Transition Information Readiness for Transition
Contexts of Care	Comparisons in Services Forming Relationships with Staff in the Adult Setting Staffing Issues
Family Issues	Sense of Loss Ongoing Support and Advocacy The Effects of CF on the Family

7.4: Superordinate Theme: Transition Process

This section has two subordinate themes, which are transition preparation and readiness for transition. All of the parents identified some fundamental flaws within the transition process.

7.4.1: Transition Preparation

The information the parents received prior to transition occurring appeared to be divided into two categories, written information and verbal information. Written information included leaflets and information packs, and verbal information included either a visit to the adult setting or a pre transition clinic. Visits to the

adult setting were undertaken with a combination of child and adult staff present and some adult staff visited children's services to undertake the clinics. With regard to written information, Jenny identified that, *"Mmm, yeah, we had a pack. I think I've still got it in the drawer..." Yeah, and at the time we were happy with the pack*

Jenny clearly found this information pack helpful although it appears that some additional information was required.

I mean looking back now I still don't really know how it really works [adult hospital]. They have different clinics on different days...but that hasn't really been explained to us.

Sally did not really discuss pre-transition information other than to identify that there was *"...nothing written down"* as it has already been identified that her interview took a different pathway. Jeff did discuss this however, and he suggested a very different format for the information they received. His daughter Katie (the oldest in the group) transitioned from a DGH to CF adult services, and in this instance, the discussion regarding transition only took place between the paediatrician at the DGH, Jeff and his wife (Sally), which is something that was also intimated within Katie's account of her transition. As Jeff suggests that, *"I don't think we were given a lot of information..."*

Overall, the information provided to the parents did not appear to be uniform. Although Carol's daughter transitioned from the same children's services to the same adult services as Jenny's son, and the time-lapse between the two was not considerable, Carol had a different recollection to Jenny with regard to the information her daughter (Molly) received as she identifies that *"when we had to go over we did have some paperwork"*

Carol also accepted that a visit to adult services constituted part of the information she received as she identified that *"...they took us over once... we had a little look around at outpatients...looked around the ward once..."*

It seems evident from all of the parental narratives that there is a perceived lack of information regarding transition and what to expect within adult services. Given that the pre-transition information appears to be inconsistent and parents have indicated that more information was required in some areas, it is possible that this could have also affected their readiness to accept their young person's transition to adult services.

7.4.2: Readiness for Transition

The parents accepted that at a certain point in their care all young people would need to transition to the adult setting. However, although the parents all discussed transition from a slightly different viewpoint: personally, practically and on behalf of the young person, in the main, they all covered similar concepts.

Jenny was the only parent who appeared not to have any concerns regarding the transition to adult services as she identified that *“I never had a problem really...to me it’s a natural thing [transition] a progression that should happen”*.

It is possible that Jenny took this approach because she was a registered nurse and as she describes, viewed transition as a natural “progression” within the healthcare system. However, Sally took a different viewpoint when she identified that, *“...I haven’t gone out to work in the hope to give her the best care possible and so yeah, yeah it [transition] was difficult”*.

In keeping with Jenny’s comments, Jeff also identified the inevitability of transition and recognised that the adult hospital provided more specialist CF management than the DGH she was attending suggesting that, *“... at the end of the day that was the best thing for her [transition]”*.

Carol also discussed transition from the perspective of herself and her daughter Molly. Firstly, she identified that, *“Yeah, it was a big step”* and then used the analogy that, *“...it’s like going from junior school to comprehensive school really...”*.

Therefore, although the majority of the parents identified that transition was a considerable adjustment, they all recognised the inevitability of transition and the need for this to occur.

7.5: Superordinate Theme: Changing Environments of Care

Under the umbrella of this superordinate theme, there are three subordinate themes; comparisons in service, forming relationships with staff in the adult setting and staffing issues: it’s the system not the staff.

7.5.1: Comparisons in Service

All of the parents in this study were quite vocal with regard to the differences between child and adult services and this covered a range of issues, including available facilities and differences in management. Jenny started her discussion with the limited bed numbers for individuals with CF in adult service as she suggests that “...*this time he was on [alternate ward named] because they didn’t have any CF beds.*”

Although Jenny recognises that the CF unit is different within adult services, her main concern is inconsistency in care as she suggests that “.... *that each consultant has got a different view... which we never had with paediatrics*”, and that “*we haven’t had consistency at all.*”

In contrast, Sally was only able to comment on the changes that she felt had occurred within the adult setting itself, much of which related to the overall facilities for patients as she identified that “...*there’s not enough beds, ...there’s still uhm the sharing, mainly of bathrooms and toilet facilities...so it’s pretty outdated*”. Although, an element of positivity remained when Sally suggested that, “...*some of the things that she’s [Katie] related back we can have a giggle about most of it most of the time you know.*”

Jeff however, was able to recognise some differences between child and adult services as he suggests that “... *going to [adult hospital] the first time if you like, it was all a new thing and a learning experience really*”. However, Jeff accepted this in his usual pragmatic way as he recognised that, “...*you tend to, you adapt to new things as you find them*”.

Carol was the most vocal in relation to the difference between child and adult services, and identified a number of issues within this theme. One of Carol’s main concerns was that she was unable to stay with Molly when she was admitted to adult services and she explains that, “*Uhm, you’re not allowed to stay in overnight with them and I know that they are getting older but still, they may like their parents to stay*”.

Carol then makes a distinction between the CF team and the ward staff when she suggests that, “*the CF team was absolutely fantastic they were on the ball*”. However, she did not appear to have the same opinion of the ward nurses particularly with regard to the administration of Molly’s medication and identified

that, *“One nurse did give her too much medication...”* that they had to *“... ask for her nebs...and sometimes like an hour or so later they still wasn’t there, so we had to go and ask again”*.

Carol also identified that, *“quite a few times we’ve found tablets on the floor in her room... and that “I had to ask for her Kalydeco® medication a few times, that’s the super drug she’s on”*.

Another final difference that Carol highlighted was that there were less restrictions on the socialisation of individuals with CF in adult services and that as a consequence of this, Molly had come into contact with other people who had CF as she suggested, *“...they do mix [in adult hospital] and they are not supposed to”*.

The parents in this study were able to identify a range of areas where they had noted differences between child and adult services. These included issues surrounding, the inability to be resident in the adult setting, lack of facilities, cleanliness within the ward setting, medication errors and increased socialisation, all of which were clearly of concern to the parental group.

7.5.2: Forming Relationships with Staff in the Adult Setting

The parents in this study clearly identified that developing a trusting relationship with healthcare staff was important for both themselves and for their young people. It was apparent however, that not all parents felt that this was possible. Jenny for example, felt that Tom’s ability to form a relationship with staff in the adult setting was hampered by the delay between the transition process and his first admission as she suggests that, *“... they [the adult staff] didn’t get to know him and he didn’t get to know them”*.

Jenny also equates this to the ability of the adult nursing staff to care for Tom appropriately as she suggests that, *“the nurses too in the adult service are lovely, they are just nowhere near as involved. And I don’t feel like they know Tom”*.

As Sally did not actually visit children’s services when Katie was admitted as a child and did not form a relationship with staff in children’s services, it is understandable that she provided limited comments regarding forming any relationship with staff in the adult setting. However, she identified that *“...and I was accepted [by the staff] while I was there as well”* [adult services].

Jeff did not really provide any specific comment with regard to forming relationships with staff in the adult setting. However, Jeff did state that Katie, “...*doesn’t actually spend much time on the CF unit anyway...*” which would infer that in turn, he does not spend enough time at the hospital to form a relationship with the staff.

Although her daughter had only had one admission to adult services, Carol did suggest a lack of relationship with staff in the adult setting when she identified that “*Uhm, it’s not knowing any of the nurses*”. Like Jenny, to a certain extent, Carol also related that the healthcare professional’s lack of knowledge about an individual had an effect on their ability to care and related a situation that she had witnessed in adult services. Carol describes a conversation between Molly and the medical staff whereby the medical staff are insisting that Molly does not need the local anaesthetic cream that she does actually want. Consequently, this leads her to believe that the level of care provision is not as personalised within adult services as it is within children’s services.

Uhm, she’s a bit needle phobic as well. Uhm so they [staff in adult setting] were just coming in her room with a needle and saying ‘right I’m just going to do your bloods’ and Molly’s like... can I have some cream on?’ [staff] ‘Oh no no, you don’t need cream it’ll cause infection’ and Molly was like ‘no I have cream on because I have it on my port so it’s fine’. And she’s petrified! I think it’s just what she’s been through over the years [causing her to be frightened]. Uhm (pause) so they couldn’t understand that. The doctors were just like ‘no, no we’ll just do it and you know it won’t take long’. And they would get out the needle, and she would be like ‘no really, please I want cream’. Once they put the cream on she was fine.

From this narrative, Carol clearly suggests that had the staff known Molly better, they would not have tried taking a blood sample without preparing her adequately for this procedure.

Within this theme, the parents were somewhat divided as to their opinions on staff in the adult setting. Jenny and Carol, who were very involved with staff within children’s services, were quite vocal and had clear opinions with regard to lack of knowledge relating to their son / daughter equating to the ability to provide appropriate care. However, Sally and Jeff, who appeared to have less involvement, were more ambivalent, particularly as their daughter Katie predominantly administered her own intravenous antibiotics at home.

7.5.3: Staffing Issues

There were a number of situations throughout the interviews where the majority of the parents voiced their criticisms in relation to different events. However, regardless of the situation, they always seemed to settle the responsibility of these issues on the 'system' and not the staff. There was not always a large focus placed on this discussion, but it was there, interspaced within the narrative of the interviews and it is worthy of some consideration.

Jenny focused her comments on adult services as a whole and in particular the inconsistencies of the staff that they encountered. As she identified that, *"...it's a different physio, it's a different dietician... his perception is, that he sees different people every time. Uhm, but that is just adult services"* (sounds fatalistic).

Sally suggested that she had noted changes in the attitudes of staff during the time that Katie had been attending adult services when she stated that *"well you know, probably one or two, a handful of the staff really, now are absolutely, well, one hopes that they are tired rather than complacent"*.

Despite highlighting the issues of perceived complacency, Sally immediately counteracts this with suggesting that the reason for this is that staff are tired, under pressure, exhausted and that *"too much [is] asked of them"*. It is evident that she does not want to think badly of the staff, which again places the situation back onto the system and not the staff themselves.

This topic also surfaced in Jeff's narrative when he was discussing staffing numbers on the CF unit and suggested that *"...our feeling is that uhm, that as time has gone on, there's less, she's getting perhaps less, much less and less attention. And that's not a criticism of the staff over the unit or anything "*. Jeff suggests that this lack of attention relates to staffing issues as he recognises that despite increased CF patient numbers, *"...the numbers of staff hasn't increased on the ward..."*.

Carol identified her concerns in relation to patient safety when her daughter Molly was admitted to the alternate CF ward.

Oh, (pause) it was scary to know, I'm thinking she was in hospital safe, she was safe, he wasn't doing no harm...and to be fair to the

nurses, they are busy and I understand that they can't watch him
24/7. [related to intruder in daughter's room]

However, Carol did recognise that the busyness of the staff on the ward, had the potential to compromise Molly's care when she identified that *"You know over there in adults they were absolutely rushed off their feet and... we had to ask for the medication..."*

Despite Carol's concerns for Molly's safety and the lateness of her medication, she was also quick to defend the nursing staff within the adult setting by identifying that they were busy, which infers that because of this they were not at fault.

It was interesting to note that Jenny was the only parent who did not make any attempt to justify the actions of staff or to offer any comment regarding staffing numbers. Given the issues surrounding Tom's last admission and out patient's appointment, this is perhaps understandable.

7.5.4: On-going Support and Advocacy

Although it was noted from the young people's data that they were in general able to manage their own care, it was also clear from this study that parents still need to 'step up' and advocate for their young people when they were not being listened to. However, it appears that it is not always easy for them to achieve.

Jenny identified that Tom was able to care for himself when he moved out of home, but she also recognised the rapidity of the default to family 'norms' when Tom returned home, and that the expectation was that she took over the management of his care. However, although this appeared to be something that Jenny had not anticipated, it is not clear on whose instigation this occurred. As she suggests that, *"... now that he's home he's dependent on me because that's the way isn't it" (shrugs)?*

Jenny also indicated that she had at Tom's request started attending outpatient clinics again to advocate for him as *"he came home from one appointment and said 'mum they are just not listening to me'..."*

Sally also identified situations where she needed to step up and speak for Katie, but that she does so with the approval of Katie herself and suggested that *"...if she's so poorly that she can't voice things herself that needs to be voiced, I will ask"*.

The accounts related by Jenny and Sally highlight a dichotomy in the management of young people with CF, whereby on one hand, it appears that they are expected to take control of their own care and on the other, they are sometimes not listened to when they offer opinions or raise concerns regarding their management or their health.

Despite this, it is clear that Sally does recognise the need for young people to move forward and tries to enable this wherever possible as she recognises that *“...we’ve always stepped back and we’ll let her go forward”*.

Interestingly, considering that his daughter had been transitioned for the longest period of time, Jeff seemed to have the greatest difficulty in ‘stepping back’ as he suggests that, [when Katie went to university] *“then we found that our sort of grasp on her treatment and our supervision was slowly starting to slip away”*.

As Carol was unable to stay with Molly when she was admitted to adult services, she provided support for her daughter by staying at the hospital with her as long as possible. As she suggests, *“[s]o first thing in the morning and late at night [arrive and leave] but it was hard”*. However, Carol also recognises the importance of ‘stepping back’, but does recognise her personal difficulties involved in this suggesting that, *“I struggle with it to be honest with you. I keep it to myself...”*.

Within this study, the majority of parents recognised the need for young people to ‘take control’ and manage their own care. However, there was also a recognition of the need to be available to speak up and advocate for their young person when the need arose.

7.6: The Impact of CF on the Family

This theme has three subordinate themes a sense of loss, being positive and the effects of CF on the family. Although the latter theme does not strictly relate to the overarching theme of transition, this thesis does relate to young people with CF and their families, therefore I believe that it is important to include the effect of CF on the family as this was something that was raised by all of the parental participants.

7.6.1: A Sense of Loss

All of the parents in this study identified that they had experienced a sense of loss either in relation to their son/ daughter taking over their own management or related to moving away from the staff in children's services.

Jenny first identified the point when Tom decided he wanted to visit outpatient clinic on his own when she identified that "*I went to his first appointment [adult clinic] and, and, he never wanted me to go again*" (*said with some sadness*). Jenny also registered that her sense of loss extended to missing the nursing staff within children's services, when she suggested that, "*I've missed [named two CF nurses] desperately, desperately...*". It is evident that Jenny felt a keen sense of loss both in relation to being excluded from Tom's care as well as missing the relationship that she had clearly built up with the CF specialist nurses within children's services.

Sally also identified a feeling of loss, but viewed this from a different perspective as she suggested that when her daughter transitioned: "*I felt redundant if I'm honest*", which suggests that she felt that as she no longer had her daughter to care for, she had effectively lost her job.

Jeff takes a totally different viewpoint and equates transition to losing Katie altogether. As he explains that: "*I think Katie in actual fact was taken away from us...*"

As Carol's daughter was the most recent of the young people to transition, it is perhaps understandable that she still seemed to be coming to terms with her sense of loss as she recognised this as she states that: "*...I've just got to try and let go*".

Although it did not feature heavily in their narratives, it was evident that all of the parents in this study had experienced a sense of loss in some way, whether this related to diagnosis, transition or severing the relationship with staff in the children's setting.

7.6.2: Being Positive

Despite the challenges of living with a young person with a life limiting illness, all of the parents had an optimistic viewpoint and clearly tried to remain positive.

Jenny recognises her pride in Tom when he was able to leave home to attend university when she identified that ‘*I was so proud of him that he could do it all for himself*’. Jenny also commented on importance of ‘normality’ and that as a family “...*we’ve never let CF dominate us. We’ve always been very strong in that*”, which also highlights Jenny’s positive nature.

Sally only made one comment regarding positivity and relates this more to Katie than to herself as she recognises that, “*Katie lives her life to the full through all adversities...*”. However, it is apparent that Jeff has tried to encourage a sense of optimism in his daughter to ensure that she remains relatively well until improvements in management occur as he suggests that “*we’ve always tried to instil in her to look after herself because things will get better and hopefully we are getting to that point*”.

In contrast, it is clear that although Carol tries to remain positive, she does experience some difficulties with this as she suggests that:

Before she was on that [Kalydeco®] I constantly worried about the future, really, really scared of the future really, really scared of the future. Uhm, never told anyone just got on with it, but now she’s on the Kalydeco® and they said she can have a normal life expectancy, the weight off my shoulders is huge. But, there is always that little doubt, thinking of it, does it work, will it work, will it work forever? Uhm (pause), so yeah, I am scared of the future.

Much of Carol’s concern relates to what she has termed as the “super drug” Kalydeco®, and whether or not it will continue to work if used long term and as Molly gets older. Because of this, she clearly finds it difficult to settle her fears and retain a positive outlook.

In general however, all of the parents in this study were able to maintain some level of positivism and it could be suggested that this is a form of coping mechanism that counteracts the challenges of living with someone who has a life limiting illness.

7.6.3: The Effect of CF on the Family

All of the participants in this study identified that CF had had a considerable impact on the family as well as the individual who had been diagnosed with the condition. It is evident that this has the potential to place a considerable strain on the family and even alter the dynamics of the family unit.

Jenny suggested that she found it very different when Tom left home, but that following a period of readjustment, it appears that Jenny and her daughter were able to settle down to a different form of 'family life'. However, this altered again when Tom returned home recognising that "...*you don't realise how much, I hate to say it, but it's easier when he went away*". Although Jenny did not elaborate on the exact effect of Tom's return home, she evidently has mixed emotions regarding the situation. This demonstrates the impact that CF has on the family as a whole, both from an emotional aspect as well as the time factor involved in his management.

Sally suggested that due to Katie having a diagnosis of CF, this meant that she and Jeff would remain involved in Katie's care and that she in particular had discussed this with her son in law suggesting, "*I think we're lucky in as much as we are a family that can talk...*", which she clearly thinks is important. However, despite this Sally intimates that there is no real acceptance of the diagnosis of CF as she suggests that: "...*I don't know about acceptance [living with CF] you know, it's like a little knife going into you each time – it never gets any easier*". Jeff also identified that Katie's diagnosis of CF had influenced their decision not to extend their family and that "...*we decided not to have any more children because of that*".

Carol's discussion took a different viewpoint as she highlighted the problems surrounding Molly's frequent hospitalisations prior to commencing on Kalydeco® and the difficulties she faced trying to give appropriate levels of attention to all of her children suggesting, "...*they [other children] would have to go down my mum's for two weeks*", and that she "...*found it hard trying to split myself three ways... Trying to make sure that the other two were alright as well...*".

It is evident therefore that CF has the potential to have a far reaching effect on the family as a whole, and not just the person diagnosed with CF. This was an issue raised by all of the parents in some way and although it does not directly relate to transition, I believe that it was important to highlight this within the thesis.

7.7: Chapter Summary

In summary, the main findings of this chapter were that;

- Parents recognised the need for transition and were not resistant to this.

- Information provided pre transition was not always relevant and some required information was missing.
- In general, parents missed the relationships they had with staff in children's services and experienced a sense of loss following transition.
- Overall, parents felt that staff in adult services did not know their young person well enough and that this impacted on their care.
- Changes in care provision between child and adult services were noted.
- Although some parents had concerns for the future, in general they had a positive outlook.
- Regardless of their age there were occasions when parents needed to be an advocate for their young person following transition.
- Parents wanted to have a continued involvement in their young person's care and that were concerned that if they were not able to do so, this would have the potential to lead to an inadequate level of care provision.

7.8: Reflection

All of the parents in this study were generous with their time and gave me the impression that they were pleased that someone was prepared to listen to their stories. However, after reflecting on Sally's interview in particular, I did feel that I had been manipulated to a certain extent as Sally's need to tell her story about Katie's diagnosis had overridden my objective of finding out about her experience of Katie's transition. Therefore, I should have ensured that the interview remained more focused on transition as opposed to allowing it to fulfil Sally's agenda. I believe that I let this happen because I had difficulty in separating the researcher (which I was supposed to be) from the nurse (which I was). So when Sally shared her experience of Katie's diagnosis, and her struggle as a young and recently bereaved mother, trying to have her well founded concerns listened to by healthcare professionals, I listened to this as a nurse not as an impartial researcher, and as a nurse, this opened up a range of emotions for me. Mostly I was annoyed that Sally's concerns had not been heard, as to me, her child's condition was obvious. Repeatedly hearing Sally's story via the audio recording,

with the anguish and despair in her voice through her tears, as she retold this story over 30 years after the event, eventually brought me to tears. This does not often happen to an 'old hospital trained nurse' like myself but Sally's story in particular had a profound effect on me. However, I realise now that this was a mistake and that in this situation, I should not have been distracted or swayed by emotion and empathy. This would have enabled me to keep more focused on my original objective.

However, in different ways, all of the parents provided me with a personal insight into what it was like to live with someone who has CF. They shared their concerns and optimism and sometimes, I was provided with information that I had not expected, which really highlighted to me how privileged I was that the parents took the time to share their stories with me for this study.

Chapter Eight

Linguistic Analysis

8.0: Introduction

This chapter evolved from awareness, during the analysis of the participants' interviews, that metaphor and specific elements of language were commonly used by the participants to describe their experiences.

Participant experiences may exist outside language but as Weedon (1987) points out, it required language to articulate that experience to other people and to make that experience more easily understood. This linguistic interpretation of the young people and parent's experiences will concentrate on their use of language and specifically their use of medicalised and emotive language (Smith et al. 2009). It will also consider binary opposites and poststructuralism (Derrida 1973, Chandler 1994). It is linked to the postmodern belief of multiple truths in that there are a diversity of meanings and understandings making up the person's life-world, these being contextually, historically and culturally influenced. This links back to Gadamer's historical approach to the phenomenological interpretation of texts. Therefore, the IPA thread and focus is maintained.

Within the interviews, language was used to try to establish a shared understanding. However, it appeared that at times certain aspects of language were used specifically to make ideas and issues that were difficult for the participants to express emotionally, accessible to me and a potentially wider audience. As I became more deeply immersed in exploring the participants' experiences, I became aware that the relationship between experience and language was fundamental to me in achieving an understanding of the young people and the parents' experiences.

Attempts to achieve linguistic understanding, were compromised by the 'poststructural' dichotomy that the meanings of words are embedded in the person's deliberate choice of language, but achieving an understanding of the precise meaning of their words, and particularly in this instance, their experience is problematic, as the language used rarely conveys the complete sense or meaning. This is not unusual, as it is suggested that the use of language does not give the whole picture, as something is often missing (Derrida 1973).

To structure and manage this part of the analysis, two questions were used to guide this development of this chapter of the thesis; how might a focus on the use of language a) contribute to understanding the participants' experience, and b) its meaning to the participants? This question was derived from Shinebourne and Smiths' (2010) study of the language of addiction and supports the double hermeneutic activity advocated by IPA (Smith et al. 2009).

8.1: Theoretical Background.

In IPA, and for this thesis, the specific purpose of exploring the language used by the participants in their interviews is to provide an adjunct, or supplement, to their descriptive and interpretive accounts. The language used by the participants specifically helped them to articulate their experiences and provided rich ways of illuminating their stories. Binary opposites were also present in the stories of both participant groups, specifically that of good and bad experiences. Binary oppositions are ways of constructing or creating layers of meaning in texts. Saussure (1983) suggests their purpose is to maintain and reinforce a society or culture's dominant ideologies, their shared theory of meaning. They occur naturally in the language of members of the same group as is evidenced in the participants' stories.

The young people's and parents stories and their use of language appear to constitute their being and their life-world, enabling them to articulate some of the more existential aspects of their experience (Greenhalgh and Hurwitz 1999). The place of language in the description and interpretation of experience lies along a range between the phenomenological concept that experiences come before language (Husserl 1998), and the post-modern idea that 'experience itself is a construction of the language one speaks' (Derrida cited by Polkinghorne 2005). The analogy of an author struggling to find the right word to describe a feeling or thought makes it clear that experience is more multifaceted than language and that it informs and puts right the words people use to express it (Gendlin cited by Polkinghorne 2005). The middle ground, which helps in exploring the experience of participants in this thesis, is that, "[e]xperience is more complex and nuanced than can be expressed in literal language" (Ricouer 1978 p147). Therefore, Ricouer (1978) suggests that the use of figurative expressions of speech such as narrative will capture the richness of the experience and open up the meanings of that experience.

8.2: The Process of Exploring Language

The approach used in identifying and exploring how the participants, describing, communicating and sharing their experiences was consistent with the required elements of IPA linguistic analysis. In the early stages of analysis there were particular uses of language in the interviews that emerged with little effort on my part. Shinebourne and Smith's (2010) paper, which discussed 'communicative power of metaphors' helped legitimise my approach to exploring how the participants talked about their experiences, *how* they said what they said, (rather than *what* they said). This offers another perspective in attempting to achieve the 'double hermeneutic', which is for me the researcher, to try and make sense of the participant trying to make sense of their experience. I particularly focussed on the participants' use of medicalised and emotive language in exploring their more personal and problematic experiences.

The process was undertaken as discussed in previous chapters following the descriptive analysis of the individual participant interviews, each transcript was revisited to focus on the use of language. Its purpose was to facilitate greater insight and understanding by considering the more 'hidden' aspects of the participants' experience.

8.3: Discussion

The individual participants' use of language was not always easily discernible. On revisiting the transcripts there emerged much similarity, perhaps reflecting a shared culture and understanding of the particular experiences associated with transition and cystic fibrosis. The major themes emerged in the use and choice of language, these were resonant with existing literature and were familiar to me from clinical practice when thinking about my experiences of caring for individuals who had CF. For both groups participating in this study, there is likely to be a shared language and understanding. As a healthcare professional my knowledge base was partially helpful in sensitising me to identifying medicalised language in particular. However, not all of the participants' use of language was enlightening, for example, Ben's language appeared rudimentary and was used to provide a largely factual account of his experience.

8.3.1: The Young People

As a group all of the young people talked more about their experiences in a way that demonstrated familiarity with the medical and healthcare systems for

example with their relationships with healthcare professionals. The words 'nice', 'fabulous' and 'friendly' were used by the young people to refer to the healthcare professionals from either the child or the adult setting. Karen was the exception when she identified that "...I've built a fantastic relationship with the adult team...".

Ben was the only participant in this group who compared the staff between both services when he suggested that:

Yeah the doctors in the [named hospital] were nice, like they took care of me really well, but it's the same in [named adult hospital] there's still really good nurses there and they specialise in CF.

Molly commented that she had "...met some of the CF team and they seem nice, and Katie recognised that the adult staff "... were fabulous, friendly and helpful..." It appeared from these comments that the participants felt that being nice, fabulous and friendly were really important, and Ben, took this a step further when he seemed to consider that being *nice* equated to providing good care. Therefore, following on from this, it would be easy to suggest that if the perception of young people is that nice, friendly healthcare staff are more caring, then it must follow that they believe staff who do not display these perceived qualities, would not be caring individuals. This could have the potential to affect the young people's relationship with healthcare staff and therefore affect their overall level of service provision.

The young people in this study had all been diagnosed in early childhood and had 'grown up' with the knowledge of having CF and it was evident that they were familiar with the system in some of the language they used. This included the use of the various abbreviations used within the healthcare setting. For example Karen identified that, "...I never had any of my IV care like on a children's ward or anything...I was always cared for on the YPU..." Here Karen uses the standard abbreviated term for intravenous (IV) and also the recognised abbreviated name of the ward (young people's unit) at the hospital where she received care in children's CF services. Ben recognised that he could "...do my physio..." and Katie also mentioned "...home IVs".

The use of this medicalised terminology also crossed over into their descriptions of daily care as Karen identified that she could "...do the majority of physio myself

... [had] ...*adjunct physio*" and discussed her "... *port....*" [Portacath]. Ben spoke about "...*antibiotics...*" Molly, referred to her "...*nebulisers...*" and Katie when she referred to her IV antibiotics, suggested that, "... *I do them myself...*" It was clear that all of the young people understood and were comfortable with, using medical terminology and this could relate to the fact that they had grown up surrounded by people using this terminology, so it had become familiar to them. Building on this, the young people and in particular Karen and Katie, could also be considered to be expert patients (Taylor and Bury 2007). Therefore, it would be understandable for them to use the appropriate terminology linked to their condition and its management.

Despite a clear understanding of their condition, there did seem to be a part of their discussion that suggested an element of battling against the system or fighting for what they want. Karen identified that her mother often spoke for her and she indicated that "...*she sometimes forgot that I had a voice*", which suggests that Karen's mother felt she was unable to speak for herself. However, Ben, Molly and Katie related their comments more towards battling the system. There seemed to be an undercurrent in Ben's interview regarding his move to adult services and the fact that he needed to move to another hospital trust, as he described this as "... *a pain*" indicating that he found this to be an inconvenience and annoying.

Molly commented on the fact that her mother was unable to stay with her and was clearly unhappy regarding the conflicting information she received. As she explains:

'cause it's not fair telling me yes and then other people telling me no because I was like really thing about it. Like I didn't really, I wasn't bothered, I was bothered actually.

In her description of this, Molly used the word 'bothered', which is a common colloquialism used by young people. To say that she was "*not bothered*" suggests that she was indifferent to the situation, but then counteracting this with "*I was bothered actually*" contradicts the previous statement and indicates that although she presented a front of being indifferent, she was unhappy with the situation overall.

There is an expectation in adult services that the involvement of parents will be reduced and that young people need to be self-caring. However, this is not always what young people want and Katie gave the impression that she had to battle for this as she identified that “...even now aged 33 my parents are still involved quite a lot and that’s the way I want it”. Stating “...and that’s the way I want it...” suggests that Katie may have had to argue this point at some stage to continue including her parents in her care.

Emotional language was also present in their stories, which perhaps added weight to the difficulties associated with certain aspects of their care and transition to adult services. In one short section of her interview Karen used the word ‘control’ on three different occasions in relation to her management of CF, “*should be in control of...I was in control of taking my medications...I was in control of doing my physio*”. The repetitive use of this word is significant in that it could be conveying that Karen felt that it was more important for *her* to be *in control* of her CF than *it* to be *in control* of *her* and that by being in control of ‘it’ gave her a sense of empowerment.

Karen and Ben both used the word ‘hard’ to describe their experiences of managing their care. Karen, recognised that managing her care during her first year in university was “... *hard, really hard...a really hard year...really hard*”. The repetitive use of this word seems to be Karen’s attempt to sum up the difficulties that she faced within a short period of time and the strong emotional impact this had on her overall. Ben also suggested that due to his lifestyle (work and study) he found it “... *hard to do my physio and stuff it’s hard to fit it all in*”. The emphasis on and repetitive use of the word ‘hard’, indicates the level to which the young people consider the impact that managing their care has on their lives.

In contrast, Molly and Katie spoke about their transition to adult services. Molly indicated that she had been “...*nervous*...” about moving to adult services, whereas Katie recognised that she had been “...*really anxious*...” and that adult services had been a “... *bit of a shock*...”. Being nervous, anxious and shocked, were all emotive words used by the young people to explain their feelings regarding their transition.

However, Katie appeared to have readjusted quickly following transition as she used the metaphor “*better than sliced bread*” to explain how she felt about this.

To be better than sliced bread is a common term generally taken to mean that something is 'better than the best'. Therefore, by stating this, Katie is indicating the importance she placed on making the transition between child and adult services.

The age of the young person also appeared to impact on their use of language and how it enabled an understanding of their experience. Although the young people were drawn together as one homogenous group, other than having CF, they actually had very little in common. Two were 'teenagers' and single and two were older and married. Consequently, their language styles were different, and there were limited similarities noted within the transcripts. Both Karen and Katie spoke in a confident manner and their discussion was generally fluid and articulate, whereas both Ben and Molly's vocabulary was limited at times and in keeping with many young people of their age, their discussion was punctuated throughout, or ended with, with the word "*like*" as the following example from Ben indicates:

...Like you get more freedom. Like you had your own room in both hospitals, but like, I don't know like, there is more freedom, like you could go wherever you want...

However, regardless of the way in which the young people expressed themselves or the words they used to describe their experiences, they were able to provide a coherent account in their own words, of their transition from child to adult services. The following section will discuss the analysis of language used by the parents.

8.3.2: The Parents

In general, as a group, the parents were more verbose and their interviews on average lasted longer than those of the young people. In contrast to the young people, the language the parents used was more fluid and varied. All of the parents were articulate although some of them, for example, Sally and Jeff appeared to have their own agenda's and their discussion tended to vary from transition to their own topics of interest. For Sally, much of this focused on her own health concerns and for Jeff, this related to what he considered to be the politicising of healthcare in Wales.

The transition from the parents' perspective appeared to relate to their loss of control and involvement. Although it was not only with words that the parents

expressed their feelings and tone of voice was also important to recognise. This relates to *how* participants said things as well as *what* they said. Jenny recognised the loss of involvement in Tom's care with some regret when she suggested that "*I went to his first appointment [adult clinic] and, and, he never wanted me to go again (said with some sadness)*".

Sally indicated that she felt "...*redundant...*" and given that she had developed agoraphobia and was housebound, it seems that she used this analogy to liken her care for Katie as a full time job. Therefore, when Katie transitioned to adult care, Sally effectively 'lost her job' and became redundant.

Jeff took a different approach to this and he identified that transition meant that Katie was "...*taken away from us...*", which is an unusual analogy to make as he implied this was a forced and not a negotiated action and that in some way, Katie had been removed from their care. Equally, Carol suggested that she had to "...*try and let go*", again implying a forcible removal, or a tug-o-war, between holding on / letting go and involvement / lack of involvement in care.

Similarly to the young people, the parents were also able to describe situations using very knowledgeable medical language, which incorporated accepted medical abbreviations and this was particularly so regarding Jenny and Carol. For example. Jenny identified that, "...*we've done IV drugs everywhere...*" and then related to Tom's hospitalisation "...*it's a different physio, it's a different dietician...*".

Although Jenny's use of terminology would be understandable as she herself was a registered nurse, Carol was equally conversant with medical terms. Carol recognised that Molly had been given "... *too much medication...*" that she was unhappy with the "...*sterilisation with her port...*" that she had to "...*ask for her nebs...*" and that Molly was "...*needle phobic as well...*", which she felt was cause for concern when staff were indicating that they were "... *just going to do your bloods...*".

This use of medical terminology highlights the familiarity parents develop with the healthcare system. Being conversant with the language used by healthcare professionals would allow parents to have a greater understanding of what was happening surrounding the care of their young person. It is also possible that this

has become a 'learned trait' as understanding the terminology also allows parents into the inner confines of the healthcare system.

One of the parents' choice of language appeared influenced by her own medical concerns and how this impacted on her support of her daughter. Sally described at length the situation surrounding her battle to have her daughter diagnosed and how this ultimately impacted on her own health and wellbeing, and an eventual diagnosis of agoraphobia. Her story was characterised by really overt emotive language and obvious distress. Prior to the narrative excerpt below, Sally had already identified that she had experienced the deaths of four close family members in a matter of weeks and then she continued:

Katie was born in the August and my mum was very poorly (pause) uhm I felt very strongly there was something wrong uhm (pause) went repeatedly to the doctors (pause) uhm wherever we went, if there was a nurse I would go – all the symptoms and blah blah blah (pause) dismissed! And then mum died (long pause) and uhm (pause – composing self)...I was told that I was depressed because my mother had died. Uhm I said my mum's died and the pain is great there is something wrong with my child uhm (pause) clinics (trying to compose herself) and (becomes tearful) told I was a despicable mother (cries – speaking through tears) to enjoy her (long pause) throw the nappies away don't constantly study them (pause) when I kissed her the salt was probably in my mind (pause). Anyway, then Jeff's job changed and uhm we had to move... to and I found that a wrench – horrendous nevertheless...

When a diagnosis was made, Sally identified that she was:

*Uhm relieved that I wasn't going loopy (twirled finger near forehead). Yes of course I was grieving, for my mother, for my father, my father in law, but **you know, you know** (emphasised strongly) your own child. And uhm, I think the worse of it was a Doctor a Lady Doctor (emphasised and said with some contempt) uhm pause, asked me if I knew the word Munchausen's (paused, tearful, very emotional but trying to compose herself, breathes out and fans her face with her hand)...*

Sally uses a series of words to emphasise the situation and her feelings surrounding this, that she had been “dismissed” that she was a “despicable mother” that the situation was “horrendous”. This must have been a difficult time for her with what appeared to be limited support, especially as it appeared to be suggested that she had “Munchausen’s” [by proxy]. Although Sally may well have been depressed, as she put it, she was pleased she was not going “loopy”, which indicates that at some stage either she felt or someone had suggested that she was ‘losing her mind’.

Although the other parents were not so emotive with their speech and gestures, emotional aspects were noted in all of the parent's narratives. Jenny identified that *...“I’ve missed [named two CF nurses] desperately, desperately...”* and spoke about the emotional *“...roller coaster...”* of living with CF. Jeff recognised that Katie's diagnosis *“...shook me”*. Likewise, Carol recognised that in relation to Molly's transition *“...I struggle with it...”* and that when she had found out about the intruder in Molly's room she suggested that *“...it was scary...”*.

The use of language for the couple who were interviewed was similar although this was difficult to gauge as their interviews took different pathways. Sally's interview, which was highlighted earlier in this chapter, tended to use emotive language as well as being emotional in nature. In contrast, Jeff's interview was more measured and reserved and it was clear that he was thinking before he spoke as the following extract suggests:

...that's not a criticism of the staff over the unit or anything we're, 'cause we've, we realise it's just, [choosing words carefully] there's a numbers thing, it's down to numbers and finances at the end of the day.

Jeff also deferred frequently to Sally potentially being able to recall more information that he could as his narrative was interspaced with comments such as *“...Sally will have a better memory...”*, which could suggest that Jeff recognised that Sally had recounted the story of Katie's diagnosis and subsequent management on more than one occasion.

Similarly to the young people the parents in this study were able to provide clear and coherent accounts of their experiences and used a range of language to achieve this. It was also evident that they were familiar with medical terminology and this was interspaced throughout their narratives.

8.4: Conclusion

The participants' use of language as described in this chapter provided a greater insight and understanding of the more personal complexities of their experience and the specific issues associated with living with a long term condition as either a parent or a young person with cystic fibrosis.

Chapters Six and Seven the discussion chapters, have together with this chapter attempted to broaden the understanding of the experiences of both participant

groups by shedding light on the complex factors involved in the transitions of care. The next chapter will provide a discussion based on the findings of this study.

Chapter Nine

Discussion

9.0: Introduction

Chapters Six, Seven and Eight reported on the analysis stage of this study using an IPA approach (Smith et al. 1999). This included the process of making notes and identifying preliminary themes, drawing together the preliminary themes and cross referencing these between participants to identify their shared experiences in addition to the linguistic analysis. For both the young people and the parents, three superordinate themes were identified. As the aim of this study was to explore experiences of transition, it is understandable that the superordinate themes for both the young people and the parents are the same. However, within these superordinate themes, there are subtle differences noted within the subordinate themes. The overarching superordinate themes as well as the subordinate themes for each participant group have been identified in the table below.

Table 22: Superordinate and Subordinate: Themes–Young People and Parents

Young People	
Superordinate Themes	Subordinate Theme
Transition	Transition Preparation Transition Process Impact of Transition on Young people
Contexts of Care	Changes and Differences Managing their own Care Relationships with Staff
Family Issues	Parental Feelings Continued Parental Involvement
Parents	
Superordinate Themes	Subordinate Theme
Transition	Pre - Transition Information Readiness for Transition
Contexts of Care	Comparisons in Services Forming Relationships with Staff in the Adult Setting

	Staffing Issues
Family Issues	Sense of Loss Ongoing Support and Advocacy The Effects of CF on the Family

Moving from child to adult healthcare services necessitates making and accepting change and this is where the Bridges Model of Transition (BMT) sits within this thesis. BMT has three main phases, the ending, the neutral zone and new beginnings and the way that the three phases of BMT sit within this thesis can therefore be clearly demonstrated. Paradoxically, BMT starts with an 'ending' although this can logically be related to the first part of the transition process whereby the young person and parents need to bring their relationship with children's services to an end.

Table 23: BMT Applied to the Superordinate and Subordinate Themes

Ending	Neutral Zone	New Beginning
Young People		
Preparation	Changes and differences	Managing their own care
Transition Process	Impact of transition on YP Relationships with staff	Continued parental involvement Parental feelings
Parents		
Pre-transition information	Comparisons in services	Sense of loss
Readiness	Forming relationships with staff in the adult setting Staffing issues	On-going support and advice Effects of CF on the family

Therefore, using the superordinate themes to structure the remainder of this chapter, the three themes that will be taken forward for further discussion are; Transition, Contexts of Care and Family Issues. Although the BMT will be discussed in relation to the content of these themes, it does not necessarily mean that the BMT is presented chronologically (Ending, Neutral Zone, New Beginning) within the subordinate themes, as although they all 'fit' within the superordinate themes, some of the subordinate themes have the potential to sit within more than one section of the BMT, which would be in keeping with a non-linear approach to transition.

This chapter will be presented in two main sections, with the first part discussing the findings from the young people's perspective and the second part from the parental perspective. The conclusion will then draw the discussion together as a whole. These themes will now be discussed in more detail and placed within the existing literature as well as identifying their relationship to the BMT.

Earlier in this thesis (section 2.3), it was identified that young people and parents encounter considerable differences when they make the transition from child to adult services. Within children's services, family centred care (FCC) is the preferred model of care delivery, parental participation is encouraged and depending on the age of the patient, a considerable amount of negotiation occurs between parents and staff (Ahmann 1998). Consequently, it is generally the parents who receive first-hand information, are provided with investigative results and are, in general, gatekeepers of the knowledge that eventually filters through to their child or young person (Sawyer et al. 1997). This differs considerably with adult services whereby it is the individual (patient) who receives the information and is responsible for managing their own care. Therefore, in relation to the preparation for transition, FCC could be viewed as potentially hindering as opposed to helping the process. It is noted that the longer young people spend in children's services, the greater the emotional bond there is with healthcare staff (West and Mogayzel 2016). Given their involvement with children's services, the same could apply to parents. The strong emotional ties to children's services felt by many young people and parents that have been fostered by the delivery of FCC mean that potentially both young people and parents experience a transition period as they move from child to adult services.

The difference in care delivery is the first major change that young people and parents encounter. However, if they are unable to manage change, they need to be supported and change should be facilitated as opposed to forced (Bridges 2015), otherwise the alternative of disengaging with the system would potentially compromise the overall health and well-being of young people and lead to an increased level of morbidity and mortality (Wong et al. 2010).

9.1: Transition: Young People

The need for appropriate transition services has previously been identified earlier in this thesis in section 1.7. The way in which the transition process is facilitated has the potential to have a lasting impact on the young person and although a

“smooth transfer” (Touchman et al. 2010 p 587) is desirable, this does not always occur (Crowley et al. 2011, Gleeson and Turner 2012).

Based on BMT, if transition heralds the end of the young person’s association with children’s services, then they need to be adequately prepared for this. The fact that young people need to be provided with appropriate levels of information prior to transition has been well documented (Viner 2003, Coleman and Berenson 2004, Shaw et al. 2004, Shaw et al. 2006, Viner 2007, Al-Yatem 2012) because without the appropriate level of knowledge it would be difficult for young people to develop an understanding of, and embrace the changes within the adult setting. Providing information can also help the young person develop as an autonomous individual, enabling them to take control of their own management and be an active participant in the transition process (Wong et al. 2010). The findings of this current research supports this as identified in the following sections, which use the superordinate and subordinate themes to structure the discussion. The exception to this is that the under the heading 9.1.1 Transition Preparation, discussion surrounding preparation and the transition process have been combined.

9.1.1: Transition Preparation

Although the level of written information provided by either child or adult services did not focus greatly in the young people’s narratives, the majority of young people in this current study did mention this. Some level of written information regarding their transition to adult services, had been provided by children’s services, although this did appear to be variable. For example, Molly identified that “[t]hey [children’s services] gave me lots to read” whereas Katie suggested that “*I think I did have some information, leaflets and things, yeah*”.

In this study, the majority of young people did not identify that they required any *specific* information prior to transitioning, as for them, what appeared to be most important at the time, was that they were actually making the transition, because as Katie identified, this was “*the best thing since sliced bread*”. Consequently, any information they felt they would have liked to have had prior to transition, was determined after several admissions to adult services, when they had reflected on what information might have been helpful, and would have lessened the impact of the differences between the two settings. For example, in her comment below, Katie suggested that despite being ready to transition and being able to

manage her own care, she still needed to come to terms with the differences between child and adult services.

I had got so used to the way that the hospital worked...and when I did move over to the adult team although I was self-sufficient as a patient, you know I was really independent, it was a bit of a shock.

However, the provision of written paperwork was not the only information recognised by young people as they also recognised pre-transition clinics and a visit to the adult hospital as being provided with information.

As identified in Chapter Two, it has been acknowledged that to enable the provision of the best level of care to individuals who have CF, management should be undertaken in specialist centres by multi-disciplinary teams (Flume et al. 2001, Doull and Evans. 2012). Where young people are not managed within a specialist children's CF centre, a form of hybrid shared care is provided between regional centres, under the guidance of paediatricians in the children's CF centre. However, this generally ceases at transition, as all adult care is usually provided in one location. Therefore, the majority of young people will have to move geographically to the location of the adult setting to continue their care (Langton Hewer and Tyrell 2008). This was certainly the case for all four young people within this study. Prior to their transition, Karen identified that she "... *had introduction clinic appointments with the adult team*", Ben suggested that "*we went down for like a meeting. One of the team...took us down and then she just showed us around...*" and Molly recognised that, "*I've been to have a look at the wards... met some of the staff on there [wards]... and I've met some of the CF team*". Therefore, three of the younger participants had visited the adult setting accompanied by staff from children's services and they found this to be helpful. However, in contrast Katie's situation was different as she identified that "*[o]bviously background conversations go on but I am not sure that we were aware of any of those*". Overall, however, the provision of information has been identified as being important and is in keeping with previous studies (Westwood et al. 1999, Boyle et al. 2001).

Karen, who was 19 years when she was transitioned, was the only young person to identify that she felt that she was transitioned later than she could have been as she suggested that she was "...*was kept there [children's services] for quite a lot longer than I probably should have...*". This is in keeping with earlier research

whereby young people had varied, or no real opinions regarding when they should transition to adult services (Court 1993, Reiss et al. 2005, Rutishauser et al. 2014).

In relation to the actual process of physically transitioning between child and adult services, all of the young people were ready to transition the remainder of their comments focused on *how* as opposed to *when* they transitioned. For example, Ben identified that *“they transferred me when I was like 18, I just went over”* and Molly suggested that *“they just said, you know, ‘you’re moving hospitals’*. It was Katie however, who specifically identified the rapidity of her transition when she recognised that *“it happened very quickly...there wasn’t any build up to it”*.

Molly was the only participant who voiced any anxieties prior to her transition when she stated that:

I’ve just been nervous about moving over...Just moving I think ‘cause mum stays with me, so it’s like for the two weeks that I go in, the difference like, she can’t come in with me.

In relation to Molly’s comment, this related to a specific issue and not to transition as a whole, but the fact that her mother was unable to stay with her was causing Molly some anxiety. This is in keeping with previous research regarding transition, which indicates that transition can be a stress inducing process for some young people (Cowlard 2003, Viner 2003, While et al. 2004).

In contrast, although Katie was apprehensive she was ready to transition when she did and, her overall feelings regarding transition were positive, as she suggests that:

Yeah, I was really anxious, uhm intrigued, a bit of a mixture really. Uhm, you don’t really know if you’re ready until the day and actually then, I discovered I was.

This comment highlights the pragmatic approach that Katie takes on most situations as she also identified that *“I’m quite a laid back person, so for some people it’s quite a big deal, but I’ve taken things in my stride”*.

If the ‘ideal’ transition is one that is ongoing and does not specifically relate to a single event (Gleeson and Turner 2012) it would appear that for the young

people in this study their experience of the information they received prior to transition was variable. Although written and verbal information in conjunction with visits to the adult setting can be considered to be part of the transition preparation process, this was not consistent across all participants in this study.

9.1.2: The Impact of Transition on Young People

It has been noted for some time that transition has the potential to cause anxiety and distress for some young people, (Hink and Schellhase 2006) limited information and preparation prior to transition can increase these feelings and thereby provide a negative transition experience (Sawyer et al. 1997, Cowlard 2003, Shaw et al. 2004, While et al. 2004). This is reflected in the 'Ending' section of BMT where individuals undergoing change can experience uncertainty and have reservations regarding the process as a whole (Bridges 2015). It would be easy to understand therefore, how transition could have an adverse effect on some young people.

In this study, the impact of transition on the young people interviewed was variable and Karen and Katie were the most vocal participants regarding their personal experiences. However, as part of the 'ending' process Bridges (2015) also identifies that, excitement and anticipation can also play a part, and this was certainly the case for some young people in this study. Although Ben did not appear to be overly concerned that he needed to transition to adult services, and Molly, did identify some anxieties in the first interview, both Ben and Molly seemed to have had some level of anticipation and excitement prior to transition. This could have been because they regarded transition to adult services also as a lifestyle transition or a 'rite of passage'.

Karen's comments were interesting as she appeared to reflect on her personal experience of transition as she related it. Early in her interview, Karen identified that:

I think it was a big change and I think I was, I was a bit upset. I felt like I was dumped in this new hospital with this new CF team 'cause I felt like I was (pause) I probably was wrapped up in cotton wool, at the hospital, the paed's centre.

This comment suggests that Karen could have experienced a sense of loss when she left children's services. This could have been due to a lack of clear expectations regarding the adult setting (Lugasi et al. 2010) or simply finding

herself in a new and strange environment without the support of familiar staff (Wong et al. 2010). Karen then went on to comment about the fact that several other changes had coincided with her transition to adult services and that led her to believe that she may not have been as prepared for the move as she originally suggested.

I think because the independence wasn't in moving to a new hospital and new team, I was moving out. I was moving to university, so I had to manage a new team doing normal independent things, like shopping, washing, cleaning. Starting a new uni course, a full on uni course, stressful, demanding uni course. I think it was too much at one time I do, and manage a new condition too you know. Uhm it was only about 6 months before I got diagnosed with CF related diabetes and actually as soon as I moved to the adult team, I needed a new port.

Moving out of home and starting university are considerable developmental milestones in the lives of young people (Rice and Dolgin 2008). Coupling these with changes in health status such as developing CFRD, which required management with insulin (Moran et al. 2009) as well as needing to have a Portacath® inserted (Warwick and Elston 2011) would have necessitated considerable adjustments over a short space of time. It is not surprising then that the transition process did appear to have an impact on Karen although she recognised that she did not necessarily identify this at the time, and that it was only talking about it in the interview that made her realise what an impact transition actually had on her.

I don't think in my circumstances, like I always look back on my transition as quite a good experience. I think it's only afterwards it affected me I think... it was quite stressful. Uhm, because it was just different, and was all stuff just happening all at once. And actually, it's only talking about it now, that I realise why I struggled so much in the first year. I really felt it was hard in the first year of uni (long pause – thinking) it was hard. I think it was just one too many things happening at once... 'cause it wasn't just moving from the paed's team to the adult team, it was actually moving hospitals and I think over the 19 years that I had been at the [named hospital], I had got so used to the way that the hospital worked.

Karen's comments are in line with the existing literature that leaving children's services should be unhurried, well timed and co-ordinated (Court 1993, Cowlard 2003, Reiss 2005, Rutishauser 2014). Transition is a challenging time for young people (Bomba et al. 2017) therefore, prior to transition they need a certain level of autonomy (Lugasi et al. 2010) and need to be empowered (Wong et al. 2010)

to manage their own condition (Duguépéroux et al. 2008). These issues are important as an ineffective transition experience has the potential to have a lasting impact on young people (McDonagh and Viner 2006).

In contrast, Ben did not appear to be overly affected by his transition to adult services as his main concern was that the adult hospital was further away from his home than the DGH where the children's services he attended were based. These concerns have already been discussed under section 7.3.1, Changes and Differences and will not be addressed again in this section.

Although Molly, identified some anxieties in the first interview, she was initially looking forward to moving to adult services. However, the incident that was described earlier, where she was visited by an elderly naked man in the middle of the night, changed her perception of adult services. During this experience, Molly had been unable to get out of bed and needed to press the emergency buzzer to contact the nurses. Although the nurses removed the elderly man from her room, this incident clearly left Molly badly shaken and unable to sleep and she suggested that:

Oh, every little noise then, I just woke up and I just couldn't sleep for the two weeks because that happened at the beginning of my admission. I couldn't sleep, I just, I don't know, it just scared me I wanted to go home (laughs).

Molly tried to be 'up-beat' about the situation when she suggested that "*now I can laugh about it...*" but goes on to identify that "*...at the time, I was so scared, really scared*", and then suggested that "*...oh I don't know, I don't want to go in again in case it happened again*".

It would have been unfortunate enough for this situation to occur during any admission, but even more so in this instance as it was Molly's first admission to adult services. That coupled with her initial anxieties and the fact that her mother was unable to stay with her, clearly had an adverse impact on Molly and could potentially lead to her disengaging with adult services in the future (McDonagh and Viner 2006).

Overall, Katie was the most positive regarding her transition experience as she described it as being "*...the best thing since sliced bread*" and suggested that "*...it was the right thing. I was ready*". Although Katie had, and still maintains a

close link with her parents, particularly in relation to them supporting her management, it was evident that she gained more control of her own care when she transitioned, as she also identified that “...*I think that I still have that independence and that was a good mix of that there [adult hospital] straight away*”. This is in keeping with other studies whereby young people need to become more autonomous and move away from their parents care (Lugasi et al. 2010, Wong et al. 2010), although it is recognised that for young people who have a chronic illness, this is not always easy to do (Bomba et al. 2017).

Within this study, the impact of transition on young people, was variable. Katie appeared to be the least affected, and Ben’s main concern regarding transition was having to travel further from home to receive care. In contrast, Karen and Molly were both affected to varying degrees by transitioning from child to adult services. Although in Molly’s case, the impact was felt during her first admission to adult services, for Karen, the full effect that transition had on her at the time, did not really become evident until she had talked through and reflected on her experiences during the interview. Karen recognised this herself, when she identified that “... *actually, it’s only talking about it now, that I realise why I struggled so much in the first year...*”

Preparing young people appropriately for transition, whether this is with written information, informal visits or on-going support is vital for a successful transition. If this does not occur there is a potential for an ineffectual or ‘cliff edge’ form of transition that is sudden, unexpected and rapid and as a consequence, could have an adverse effect on their overall health.

Although in the diagram depicted in Figure 2, ‘managing their own care’ sits within the BMT under ‘new beginnings’, whereas ‘changes and differences’, ‘relationships with staff’ and ‘the impact of transition’ sit within the neutral zone, they have been presented under the same superordinate theme as there is room for some manoeuvrability with regard to the concept of ‘managing their own care’. Ideally, although the ability of a young person to self-manage their care should be established by the time they reach the new beginning stage, this is still something they could be coming to terms with during the transition process and as a consequence, has the potential to span both the neutral zone and the new beginning sections of the BMT.

9.2: Contexts of Care

All of the young people in this study needed to move from one hospital to another to receive their CF care in adult services. For Karen and Molly, this meant staying within the same health trust, but for Ben and Katie, this also necessitated changing health trusts as they were both moving 'out of area'. This can be challenging for young people as this could mean changes in their management, taking more responsibility for their own care and developing new working relationships with unfamiliar healthcare professionals (Viner 2003, Zack 2003, Rutishauser et al. 2014).

9.2.1: Changes and Differences Between Child and Adult Services

It is understandable that practices will differ between hospitals and it was Karen who first noted this when she suggested that *"...when I went to the adult team, the whole appointment set up was completely different"* and that *"...that there's a lot in adults that's completely different – not spoon fed any more"*. Although Karen did not have a great deal to say regarding this, she does clearly identify that there are differences between services that need to be taken into consideration (Lugasi et al. 2010).

Ben identified the differences between child and adult services from several different perspectives, the first being the fact that he had to move to another hospital to receive care in adult services when he stated that, *"... it's nothing about the move...they were welcoming and all that...it's just the location that's all..."*. This relates to the issue that Ben was one of the young people who needed to move 'out of area' following transition and that the adult hospital was a considerable distance from his home. This clearly caused some inconvenience for both himself and his mother a fact that he highlighted later in his interview.

Transitioning to adult services appeared to be an improvement for Ben, as he identified that *"like in the [children's ward] there was no one my age"*. Ben's comment suggests that he may have experienced a sense of loneliness and isolation when he was admitted to children's services. The apparent loneliness experienced by Ben resonates with the work undertaken by Hutton (2002, 2005, 2007, 2010) in relation to the hospitalised adolescent whereby the importance of specialist adolescent wards are promoted as a way of increasing peer interaction and improved levels of care to young people. Socialisation is important to adolescents (Rice and Dolgin 2008) and although interacting with other

individuals who have CF is discouraged to prevent cross infection (Badlan 2006), if he had been admitted to an adolescent ward, the important factor is that Ben would have been able to interact with other young people of a similar age (Hutton 2010). It is perhaps because of the ability to socialise with individuals closer to his own age that Ben appeared to be so impressed with adult services.

Another issue for Ben was in relation to having more freedom in adult services. Ben identified that "*I don't know like, there is more freedom [in adult services], you can go wherever you like*", which does suggest a more relaxed approach than he was used to within children's services. This, in fact, was Ben's main consideration when he highlighted the differences between child and adult services as he suggested that:

The adult ward is better. Like you get more freedom. Like you had your own room in both hospitals, but like, I don't know like, there is more freedom, like you could go wherever you want. Yeah, they let me leave whenever I want as long as I am back in time for my antibiotics and all the physio stuff that's fine.

This issue of increased freedom in adult services was clearly of importance to Ben and this would sit within his developmental stage (Rice and Dolgin 2008) and would link to developmental concepts such as increased autonomy and decision making and enhanced cognitive development (Lugasi et al. 2011, Wong et al. 2010). However, although Ben views this as being a positive move, he does not recognise that the restrictions placed on him in children's services would have also related to his age at the time and the fact that the staff on the children's ward would have been responsible for him as a minor, whereas in adult services, he is afforded more freedom, simply because he is an adult.

Molly's main concern has already been highlighted and that was that her mother was not able to stay with her and although she recognised that this was not really possible, her issue was that she had been provided with conflicting information regarding this. She explained that:

Yeah, the nurses said, some nurses were like, 'Oh your mother can stay in with you', and I thought that's OK, then other nurses said 'no'. Which they should all have a meeting and say 'no' or 'yes' 'cause it's not fair telling me yes and then other people telling me 'no' because I was like really thing about it. Like, I didn't really, I wasn't bothered, I was bothered actually.

Situations such as this have the potential to lead to the perceptions by young people that care in the adult setting is “impersonal” and that staff are “unfriendly” (Viner 2003 p.210) (see Chapter Two). It also highlights the importance of maintaining consistency when providing care to young people. However, Molly’s request for her mother to stay with her is not unique. In a study undertaken by Miller et al. (1998) 95 adolescents were surveyed to determine their preferences regarding hospitalisation and the majority of these (84) indicated that they would like someone to stay with them, particularly “during medically difficult times” (p91). Although this study is dated, the fact that Molly also expressed the desire to have her mother present indicates that the findings of the Miller et al. (1998) study are still relevant today. Additionally, not allowing Carol to stay with Molly is in direct opposition to the recommendation made by the Welsh Government in the *All Wales Universal Standards for Children and Young People: Specialist Healthcare Services* (2008), document where it is recognised “that facilities should be available on site for parents to stay with children and young people” (Welsh Government 2008 p12). Therefore, this is an issue that needs to be addressed.

Molly also described some of the differences she had noted regarding her care in adult services, particularly in relation to her medication.

I mean the care was really good I know they forgot like when they said ‘I’ll go and bring your nebulisers’ they’d forget and it was an hour or two before they remembered and that was you know, a bit you know slacky, but other than that really good.

It appears from the above comment that Molly was trying to be diplomatic and place a positive slant on her care by stating that her care was “really good”, although she does not elaborate on the really good care, she also highlights that staff forgot to administer her medication. This can lead to as Viner (2003) observes, young people developing a lack of confidence in the care they receive and in the staff delivering it and has the potential to cause dissatisfaction in service provision.

Katie was also able to identify differences between child and adult services although her discussion took a broader approach and did not really focus on any specific events. As she suggested that:

When I did move over to the adult team although I was self-sufficient as a patient, you know I was really independent; it was a bit of a shock.

She then went onto identify that:

When I was with the children's centre, I could pop back every day even if I wasn't staying in, whereas with the adult centre you're kind of left to your own devices there with home IVs.

Katie's comment regarding "...being left to your own devices..." suggest that there is an expectation in that the young person will be able to self-manage their care when they move to adult services and this will be discussed in more detail in the next section.

9.2.2: Managing Their Own Care

Promoting self-care and self-management is a major goal in adolescent healthcare and this is particularly relevant in relation to transition. Young people who move from child to adult healthcare services need to adapt to, and negotiate through the differences in the new environment. They also need to be able to work in collaboration with the adult healthcare team to make autonomous decisions regarding their own care (Lugasi et al. 2011). This could pose problems for the adolescent as transition may occur when developmentally, they are not ready to be autonomous individuals (Spear and Kulbok 2004). However, on the whole, the majority of participants in this study appeared to be able to manage their own care.

Karen had very firm views on what she felt she should know in relation to her own health and management, which demonstrates her ability to make autonomous decisions (Spear and Kulbok 2004). When discussing the expectations of staff in adult services, Karen identified that, "*They expect you to know, because you should know... you take that medication every day and you should be in control of what you take*".

Karen then went onto identify the level to which she managed her own care:

I could reel off my medication any day now. I know what I'm on, what the dosage is and it's what's expected of you in adult...I can do the majority of physio myself and actually I've got kind of adjunct physio. I've got acapella®, PEP® mask... So things like that really, uhm (pause), you know I was in control of taking my medications. I was in

control of doing my physio... and, you know, not that you can't ask for help, because you can (pause) but you are expected to be independent.

In the above statement, Karen uses the word 'control' several times in the context of managing her care, which could suggest that she felt it was important for her to be in control of her condition rather than it be in control of her. This could also be a coping method employed by Karen to manage her condition overall (Folkman 2010).

Ben was also involved in managing his own care and was able to fit this in around his busy lifestyle although he did seem to have some difficulties with this:

Yeah with my college and stuff it's hard to do my physio and stuff it's hard to fit it all in.

Like I do all my stuff now and again but like I won't do as much as other people because like I am working as well, I go to work straight after college see, so it's hard.

I mainly just go to the gym, do stuff in college – like we are training almost every day and going to the gym in college.

Ben's comments identify some of the complexities for young people who are trying to live their lives to the full (Viner and Barker 2005) but also have a demanding chronic illness to contend with (Viner and Booy 2005). Although Ben seems a little concerned that he is not doing enough when he identified that ... *"I won't do as much as other people..."* it would appear that Ben does manage his time quite well as he juggles between having a social life, studying, working part time and managing his CF care. However, this is facilitated to a certain degree by the type of course (sports management) he is undertaking as this involved regular gym sessions, which could be aligned to his CF physiotherapy and exercise regime.

Molly did not discuss managing her own care because as outlined in Chapter Six, her interview took a different direction. Additionally, Katie only provided limited comments regarding her own management and these related to her undertaking IV therapy at home when she identified that *"I do them myself, yeah"* [IV antibiotics]. Katie presented this information in a 'matter of fact' way, and it was

clear that she was used to this process. It also highlights the level of autonomy in, (Spear and Kolbok 2004) and responsibility for, her own care that Katie experienced. This sits well with the concept of co-production whereby patients and healthcare staff work in partnership to facilitate the best outcomes of care for the individual concerned (Batalden et al. 2015). Limiting her time in hospital would also reduce the potential risk of cross infection for Katie (Badlan 2006). However, whilst limiting hospitalisation, and whilst it does have more positive than negative benefits, it also has the potential to impact on forming relationships with staff in the adult setting.

9.2.3: Relationships with Staff

If a young person with CF is diagnosed in infancy, they could have been admitted to the same children's ward for eighteen years, or even longer. Due to the nature of the FCC model used within child health, staff in children's services often develop a strong bond with young people and their families (Lugasi et al. 2010). These bonds break when transition occurs and young people and their families need to meet and forge relationships with new healthcare providers. Some young people find this easier than others and it appeared to be the case in this study.

Karen made the comparison between child and adult services when she identified that:

I think I had always appreciated how good my relationship was with all of the clinical team [in children's services]...It's like anything, if you start a new job or go somewhere new you always worry, oh gosh, am I going to have good relationship with the people that I, you know, probably will have to spend a bit of time with.

However, she did go on to identify that this concern was unfounded.

Uhm, well just to say that as I've built a fantastic relationship with the paed's team, I think I've built a fantastic relationship with the adult team. Uhm, it's taken...it did take a little while, because you've got to get to know people and get to feel comfortable, but yeah, things have been ok with the adult team.

In contrast, Ben did not discuss relationships with staff as such, as he placed this more into the context of the care the healthcare professionals provided for him.

Yeah the doctors in the [named hospital] were nice, like they took care of me really well, but it's the same in [named adult hospital]... there's still really good nurses there and they specialise in CF.

Again, Molly did not discuss forming relationships with staff although it could be suggested that her first impressions of adult staff were clouded due to her experience during her first admission. This is particularly relevant where she received conflicting advice (see section 7.3.1) coupled with the apparent lack of understanding she experienced from adult healthcare staff when she encountered the 'night visitor' (see section 6.8).

However, Molly's relationship with the ward staff was clearly different to the relationship she had with the CF Team as she suggests that, *"the CF team, I can't fault them they were amazing, they were really good... they would just come down to see if you were ok... every single day"*.

It seems evident from these comments that Molly felt more supported by and was able to build a better relationship with, the CF team than the ward staff. This is understandable as effective communication between young people and healthcare staff enables them to develop a shared understanding of problems and concerns and is the first step in effective coproduction (Batalden et al. 2015).

Katie was the only participant who did not make any comments regarding forming relationships with staff in the adult setting. This could be because Katie spent as little time as she possibly could in hospital and managed her care at home (see section 7.3.2), which to a certain extent could be viewed as a level of disengagement with the system. However, creating an effective rapport with healthcare providers in the adult setting and developing trust in new staff and the new system is vital in maintaining good healthcare outcomes for young people (Wong et al. 2010), particularly as transition itself can have a considerable impact on young people.

9.3: Family Issues – Young People

The contribution of parents to the care of their child and subsequently their young person with a chronic illness is well recognised (Callery 1997, Shields and Nixon 1998, Iles and Lowton 2010, Lugasi et al. 2011, Sharma et al. 2014) and includes practical and emotional support, acting as advocates to resolve specific issues and continuing to assist with home management. Although one of the main aims of pre-transition preparation should be to facilitate the self-management of young people (Sharma et al. 2014), this does not mean that the role of the parent does, or should, cease at the point of transition. Based on the comments from the

young people, especially Molly and Katie, the results of this study would actually suggest the opposite, in that despite transitioning to adult services, young people still value their parent's continued contribution to their care.

All of the participants in this study recognised that their transition had also had some effect on their families. It is interesting however, that although Karen and Katie were both married, neither of them mentioned their husbands within the context of family issues. Although, both spoke of their husbands during the preliminary chat before the interview commenced, they were 'invisible' throughout the actual interviews. This was an interesting point I only noted after the interviews and during the analysis stage. It is not clear why neither Karen nor Katie mentioned their husbands, it is possible that because I was asking them about their transition experience, they felt they did not need to mention their husbands. However, both Karen and Katie spoke of their parent's involvement in their ongoing care, so it would have been reasonable to expect them to mention their husbands when 'family issues' were being discussed. Alternatively, in some way Karen and Katie could have been trying to separate their 'old' lives (CF / parents / transition) from their 'new' lives (husband / the future / CF) where perhaps they were trying to give CF less of a prominent focus. Although it may have just been they just did not feel comfortable discussing their husbands with a stranger.

9.3.1: Parental Feelings

During the interview Karen's discussion focused on her mother regarding the impact that transition had on her when she identified that:

She was really upset, really, really, upset and I think she still finds it a bit weird that she doesn't come along to appointments with me now, because she wants to know the ins and outs...Uhm, it was really hard for her I think, I think for the first year. Really kind of cut up about it, uhm, but she is used to it now.

This comment suggests the difficulties in the divergence from parental to self-care, particularly for parents (Shaw et al. 2004). On the one hand, Karen was clearly ready to take over the management of her own care, whilst on the other, she recognised that this was difficult for her mother and although Karen identifies that she is "*used to it now*", it has to be considered whether or not this is actually the case or just Karen's perception of it. Although it would have been interesting

to have been able to present Karen's mother's opinion in this study, she had declined being interviewed.

When Ben discussed the impact transition had on his mother, he identified that having to travel a greater distance to the adult hospital was also an issue for her, as he suggested that:

It's the same for my mum [travel] it's a bit of a pain for her like but now I can drive it's not too bad.

When I go in for two weeks it's hard for her to come down. She's got two other kids.

Having to travel further for care may be considered to be a minor issue and one that is not really a valid concern, but this did appear to be a concern for both Ben and his mother. Additionally, Katie, who like Ben had transitioned from a DGH to the adult CF centre, also identified travel difficulties in relation to accessing support from adult services when she still lived near her parents. However, she followed this up with "[b]ut I live in [named location] now, so popping back [to adult services] now is not an issue...". By naming the location of her new home in her interview it was evident that Katie had actually moved closer to the adult hospital and it was identified that this was for ease of access and clinical support.

Unless individuals live in the city itself, the location of the adult CF centre is not on any direct public transport routes and for some people, getting to the adult CF centre could necessitate using a minimum of either a train and a bus journey or two bus journeys each way. Even for people who drive, car parking is difficult so it is understandable that Ben views this change of location problematic for both himself and his mother.

When Molly was asked how her mother felt about her transition she suggested that:

Yeah she's finding it strange you know when we move over and she can't stay there.

Molly again highlights the issue of her mother not being able to stay, but now she identifies that it is not only she, but also her mother who had some difficulty with this. However it has already been noted that young people may still wish their parents to stay with them in the adult setting (Miller et al. 1998), therefore it would

not be unreasonable to consider that parents may also wish to stay when their son/ daughter is admitted to the adult setting. The inability to do this would have the potential to increase parental stress (Streisand et al. 2001, Cousino and Hazen 2013) and dissatisfaction with the transition process (Viner 2008, Iles and Lowton 2010).

Katie acknowledges that although she was ready to transition, her parents may not have felt the same way as she suggests that:

Uhm, they could see that I was happy and comfortable, confident with the team, but yeah, I don't know how they felt about the fact that I was more independent.

Katie's comment suggests that there may have been some conflict for her parents between recognising that transition was the right thing to do and the fact that she was becoming more independent. This is in line with existing literature as during the transition process some parents express concerns that their young person will not be able to manage their own care appropriately (Westwood et al. 1999, Boyle et al. 2001, Flume et al. 2001, Viner 2002, Kirk 2008, Viner 2008). However, in this study, it became apparent that the young people were content to varying degrees, for their parents to continue to be involved in their care after transition had occurred.

9.3.2: Continued Parental Involvement

Although they did not necessarily discuss it in any detail, all of the young people in this study identified that their parents were still involved in their care in some way and it was clear that they were happy for this to continue.

Karen recognised that although her mother may not help out practically, she did still keep her informed of any changes in her care as she suggested that ".../ keep her [mother] in the loop, if anything major or different happens".

Ben identified that his mother still went with him to outpatient clinic in the adult setting when he stated that "we [mother] go down every month", but he did not identify whether his mother was actually included in the consultation itself. Ben also identified that "...she [mother] still helps out", but again he did not supply any further information regarding *how* she helped out.

Molly related her mother's involvement specifically to her admission in the adult setting and her comments were an extension on the theme of her mother not being able to stay with her. Molly recognised that because her mother was unable to stay, she spent as much time with her as she possibly could and she suggested that:

She [mother] was leaving about half ten, eleven o'clock at night and coming in seven o'clock in the morning and then she did that for two weeks as well.

It is clear that as Molly's mother (Carol) was unable to be resident, what she was attempting to do here could be seen as the 'next best thing' to support Molly during her admission. This could have potentially placed a great strain on Carol and increased the stress she was experiencing when she was trying to remain involved in Molly's care (Streisand et al. 2001, Cousino and Hazen 2013).

Katie clearly valued the continued involvement of her parents in her care and recognised in particular, the contribution they made regarding her ability to self-manage her care at home as she suggested that "...I've done home IVs where I can thanks to Mum and Dad". Although she is able to manage her own care, Katie still acknowledges the contribution both her parents make to support her as she identifies that, "...even now aged 33 my parents are still involved quite a lot and that's the way I want it". Katie then goes on to say that, "...they've [parents] always helped me, it's just made it easier for my adult life".

In some ways, these findings are at odds with previous research that suggests young people want complete independence from their parents to be able to make their own decisions and have more freedom (Russell 1996, Zack 2003, Reid et al. 2004, Stabile et al. 2005, Shaw et al. 2006), although not all of the participants in these studies had CF. Bomba et al. (2017) even identify that there is a potential for conflict between young people and their parents during the transition period when young people try to gain more control, although this could be viewed as a normal progression in adolescent development (Santrock 2001, Spear and Kulbok 2004, Rice and Dolgin 2008). However, the importance of continued parental involvement was identified by Iles and Lowton (2010) and Heath et al. (2017) suggest that parents have a vital role to play in the transition process, it is recognised that this may not be the 'norm'. However, the results of this current

study are more in keeping with these findings from the Iles and Lowton and Heath et al. studies.

Where young people do want parental involvement to continue, this should be respected, but it appears that this does not necessarily happen. The results from the Iles and Lowton (2010) study recognise that although young people may view their parents as partners, it did not necessarily follow that this was the case for healthcare providers. In this study, although staff recognised that parents *could* be partners in care, they continued to hold the belief that parents no longer had *the right* to be involved once transition had occurred (Iles and Lowton 2010). This again works against the ethos of patient focused care as it refuses to recognise the wishes of the patient and does not sit within the co-production model being promoted within healthcare services (Batalden et al. 2015).

The following section of this chapter will now discuss the results from this study in the context of the parental findings.

9.4: Transition – The Parents

Based on the comments from the parents who participated in this study, it was evident that they understood that transition was an inevitable necessity. Additionally, it was also viewed as being a positive step, as it meant that their son / daughter was well enough to be able to make the transition and take charge of their own care. However, transition is still not an easy process for parents to manage and it appears to cause considerable conflict within themselves. In the main, parents recognised that ‘growing up and moving on’ was a natural progression, a normal part of adolescent development, but what complicates the developmental process in this situation, is the presence of a chronic illness and because of this parents still feel the need to be involved in the management of their young person’s care.

9.4.1: Pre-transition Information

The importance of providing adequate information prior to transition is well documented (Viner 2003, Cowlard, 2003, Shaw et al. 2004, Lugasi et al. 2010, Wong et al. 2010, Bomba et al. 2017). Although the parents in this current study recognised that they had received information prior to their young person’s transition, they identified that what they lacked most of all was information regarding the receiving hospital. Basic information such as, how clinics were

conducted and on what days, and the use of alternative ward areas for CF patients, were some of the issues raised by the parents in this current study that they would have liked to have known about prior to transition. The need for information about the new hospital is understandable as parents would have been familiar with children's services, but adult services could be viewed as a fear of the unknown (Viner 2001a).

Jenny recognised that she did receive information both in written form and in keeping with the young people's opinions of 'information' had also had an accompanied visit to adult services. As she explains, "...yeah, we had a pack... It was a big pack... that they had lots of information leaflets in I'm sure they were given that same pack three times" (laughs)...she then explains that "...just before he went over [named] the CF nurse from here [children's services] ...took us both over there [adult services] ...the CF nurses were brilliant! [named two CF nurses]... they made it very smooth... [transition]...".

However, despite this, Jenny also identified that she would have liked more specific information particularly regarding outpatient services.

I mean looking back now I mean I still don't really know how it really works in [named adult hospital]. They have different clinics on different days and it depends on what bugs you've got what days you go (laughs). But that hasn't really been explained to us.

Sally who was part of the married couple in this study recognised that they had received limited information prior to transition when she suggested that there had been "...nothing written down". Jeff agreed with this and also identified that the information he and his wife received prior to transition was limited and suggested that:

I don't think we were given a lot of information and uhm, from memory... I don't think there was anything ever written, or any presentation or anything like that.

This was also Carol's experience when she suggested that "... we knew we were building up to going over [transition] but it was more just saying 'right you're going over' nothing really introducing us to much to it"... "you go in [adult hospital] and you don't (pause) you don't know what to expect really and everything changes". Although she did identify that:

When we had to go over we did have some paperwork with uhm, just like the phone numbers and uhm stuff about who's who and that was about it really (pause) yeah.

However, she also identified that:

Uhm, they took us over once. Uhm we had a little look around at outpatients. Uhm met a few of the nurses that were there.... Uhm looked around the ward once...

Carol then suggested:

I can't fault the CF team because they were really good but I just don't think they give enough information out on going over from paed's to adults.

Not knowing what to expect would have the potential to cause increased stress for parents (Streisand et al. 2001, Cousino and Hazen 2017) so it is imperative that parents receive relevant information regarding the adult setting prior to transition (Shaw et al. 2004). This would help to reduce their anxiety and have the potential to make the process of moving between services smoother. Additionally, not providing the parents with adequate information prior to transition seems to be illogical, as if they are adequately informed, they will be better able to support their young person. Coyne et al. (2016) identify this when they suggest that providing parents with information regarding the transition process empowers them and in turn they can help facilitate a smoother transition.

The other issue that some of the parents identified that they needed to know about prior to transition, was the possibility that their young person could be admitted to an 'alternative ward'. None of the parents who mentioned this, realised that following transition to adult services, it was not a 'given' that their young people would be cared for on the CF Unit. Jenny was the first to mention this when she stated, "...we never knew there was this [alternative ward]...and it might have been nice to be told". She then went onto identify that:

When he went in and he was 18 he was on the CF unit, uhm whereas, this time he was on [alternate ward named] because they didn't have any CF beds.

So based on Jenny's experience, it appears that the alternative ward is used when the CF Unit is full and although this is understandable, it does not always appear to be an acceptable solution for the parents. Sally in particular,

considered the use of the alternative ward unsatisfactory as she identified a situation that Katie had experienced on the alternative ward:

One time her husband to be, took her in because they were in [named area] and before he would let her go into the room [he] asked for cleaning things to go and clean it [the room] and that's not good is it?

Carol recognised the presence of an alternative ward in a different way as she linked this to care standards as she identified that “...I don't know if it's because she wasn't on the CF ward. I think if she was on the CF ward it would be a bit different”. Carol returns to this theme later as she appears to associate some of the problems Molly experienced during her admission (potential drug error, late medication and the ‘night visitor’) to her being on the alternate ward and tended to differentiate between what she called ‘the ward nurses’, who worked on the alternative ward, and the CF healthcare professionals, when she stated “*not the CF nurses the nurses on the ward*”. This will be discussed later in this chapter under section 7.6.1 Comparisons in Service.

This situation would have been unfamiliar to the parents and is further evidence of the cultural divide and change in practices between child and adult healthcare services (van Staa et al. 2011). In this study, the parents identified their young person being admitted to the alternative ward as challenging and a source of anxiety, particularly as they had not known about it beforehand. It is possible therefore, that this anxiety could have been alleviated if the parents had known of these alternative arrangements prior to transition (Viner 2003, Cowlard 2003, While et al. 2004).

Situations such as this do not instil confidence in the ‘new’ adult service for parents, particularly if they consider that the alternative ward is not providing the same level of care that they had been used to in children's services (Wong et al. 2010). It also reinforces the importance of providing clear and comprehensive information prior to transition (Viner 2003, Cowlard, 2003, Shaw et al. 2004, Lugasi et al. 2010, Wong et al. 2010, Bomba et al. 2017). This would also help to make parents ready for their young person to make the transition from child to adult services.

9.4.2: Readiness

While it is recognised that young people need to be ready to make the transition to adult services (Viner 2008), some consideration should also be given to preparing parents for the transition process. This is especially relevant if we accept that parents can help to facilitate a smooth transition for their young person (Heath et al. 2017). However, despite an apparent lack of preparation, in the main, the parents in this study accepted that transition needed to occur.

Jenny identified that for her and her son Tom, there was a 'build up' to transition when she suggested that, *"...I think it [transition process] was about over two years when he was 16-18"*, which clearly gave them some time to prepare for this process. However, possibly because she was a nurse herself, Jenny appeared to be accepting of the transition process and she suggests that: *"... I never had a problem really...to me that's a natural thing [transition] a progression that should happen...No I can't say it caused me any distress, not really..."*.

Sally felt that to a certain extent she had been prepared for Katie's transition to adult services when she identified that *"I think from a transition point of view (pause) especially from paed's, they did everything they could to get you ready for that change"*. However Sally did recognise that transition had not been easy, particularly as she had focused so much attention on Katie's care as she explained that, *"I've always been a hands on mum I haven't gone out to work in the hope to give her the best care possible and so yeah, yeah it [transition] was difficult"*.

However, a considerable proportion of Sally's interview focused on her own ill health and she returned to this issue with regard to being ready for Katie's transition.

Uhm (long pause) hands up, it was more difficult for me [transition] because (pause) before she became 18, I myself became agoraphobic uhm (pause) so... I couldn't get out to the hospitals

Sally's situation is unique in comparison to the other parents in this study, and it is clear that Katie's transition had a different effect on her and to a certain extent one that was more positive. Concerned that Katie would be further away from her when she was admitted to the adult setting she decided that *"I couldn't live my life*

like that so I got some help and then I started [treatment]..." This eventually enabled her to visit Katie when she was admitted to adult services.

Jeff started his discussion by recognising that his daughter had transitioned "... *slightly after she was 18*". He then went onto identify that "... *I think that initially, we were perhaps a little bit reluctant to do it [transition]*". Although he doesn't specify who 'we' were it can be assumed that he meant his wife Sally, although this reluctance to transition is not reflected in her comments or in Katie's perception of transition (*better than sliced bread*). However, Jeff then made another interesting comment when he identified that:

I think Katie in actual fact was taken away from us if you like as much as her having to travel to [named adult hospital] and have these things [management] done.

It appears that by Jeff stating that she was "...*taken away from us...*" he seemed to be equating Katie's transition with a 'loss of control' in some way, whether he considered this to be just related to her management or to her as a whole, it is not clear. Jeff did seem to be more than a little unhappy that he no longer had any actual input into Katie's care, although his reluctance to 'let go' was understandable. Jeff and Katie did appear to have a very close bond, possibly because Jeff was so involved in Katie's care when she was a child as he was the person who stayed with her when she was admitted to hospital.

Jeff in particular appears to 'blame' transition for his loss of input into Katie's management and there seems to be a tension here between his perceived responsibilities to provide care versus Katie's autonomy and her ability to manage her own care. Increased autonomy is a normal part of a young person's development and the young people in this study do seem to have viewed transition as a part of 'growing up' or a 'rite of passage'. However, in Jeff and Katie's situation 'growing up' is complicated by Katie having CF and also seemed to coincide with the transition process. Therefore, it is possible that Jeff 'blamed' both transition and adult services for having "*taken away*" his daughter as a way of conceptualising his feelings; a reification of his feelings of helplessness regarding a situation he could not change.

Although Jeff did not appear to be fully ready for transition to occur he did not appear to make any attempt to "sabotage" (Viner 2003, p2685) the transition

process as some literature suggests. On the contrary, Jeff recognised that transition was actually the right thing for Katie as he suggested that, “... *you know at the end of the day that, that was the best thing for her [to transition]*” and then went on to identify that the reason for this was that

...we knew that she was outgrowing the paediatric unit not so much in terms of age, but uhm, but in the fact that their knowledge of the condition wasn't as great as it was in [named adult hospital]

Therefore, although Jeff may not have liked the idea of transition, possibly because he just did not like the idea of change (Wong et al. 2010) he did accept it and recognised that it was the best option for his daughter in relation to her management.

Carol's comments regarding being ready for transition were minimal, but she did view these from two perspectives: her own and her daughter Molly's. With regard to her own feelings she just identified that it was “... *a big step*” [transition] and reinforced this when she discussed this from Molly's perspective, “...*it's a big step, it's hard, it's like going from junior school to comprehensive school really (pause). It is that big step for them*”. Equating transition to moving from primary to secondary school seems to be a way for Carol to normalise the situation and place it in the same context as real world events (Smith et al. 2009), which may have made it easier for her to process and come to terms with.

9.5: Contexts of Care

All of the young people in this study needed to change hospitals and two needed to move 'out of area' and therefore change hospital trusts to receive their care in the adult setting. This can be equally as difficult for parents as for young people as not only do the parents need to learn the new system, including the greater focus on patient centred care (Kirk 2008) as opposed to FCC but they also have the potential to be excluded from negotiations in the care of their young person (Iles and Lowton 2010) and no longer have 'open access' to their hospitalised young person (Reed-Knight et al. 2014).

9.5.1: Comparisons in Child and Adult Services

Having spent so much time in and becoming familiar with children's services, it is perhaps understandable that parents in this study made comparisons between adult and child services. Based on their comments, the experiences of the

parents were less than positive, although this could be recognised in some situations as lack of familiarity and moving out of their comfort zone. Within the BMT this would mean that the parents were still well within the ending stage, where they were experiencing reservations with regard to what was to come, but moving towards the neutral zone, where they experienced some confusion and were therefore making comparisons in care (Bridges 2009).

Jenny's main concern was the inconsistency between staff in relation to Tom's management and she recognised that this had not been an issue in children's services:

Jenny then goes on to clarify this by stating that:

It's different...it feels like, our experience has been that each consultant has got a different view and the treatment changes whichever consultant you are with, which we never had with paediatrics whereas we haven't had consistency at all.

...it's a different physio, it's a different dietician. I am not sure how many dieticians they have up there mind, but you feel, his perception is, that he sees different people every time. Uhm, but that is just adult services (sounds fatalistic).

Jenny's comments can be related to the "cultural divide" between child and adult services identified by van Staa et al. (2011 p821), which they suggest serves to make transition even more difficult for young people and their families. As practices differ between child and adult services this can present a 'culture shock' for parents, particularly if they do not view the differences between the services as an improvement.

Sally could not really make comparisons between child and adult services as she had not accompanied Katie to hospital when she was admitted prior to transition. In contrast, what she tended to do was to make comparisons between the time Katie had been transitioned to adult services and the time I had interviewed her. However, for Sally her main concerns focused on lack of facilities in the adult hospital:

...that's my biggest concern [lack of facilities]...there's not enough beds, but also it's quite outdated... You know there's still uhm the sharing, mainly of bathrooms and toilet facilities...so it's pretty outdated.

Sally focuses her comments on the adult hospital and does not clarify whether she is discussing the CF Unit or the alternative ward that has been identified by some of the other parents. Sally is not unique in her concerns regarding the need to make improvements in adult CF care. Madge et al. (2017) undertook a European survey of several adult CF centres, although the adult centre where the participants of this current study were transitioned to, was not included. Overall, 98 adult CF centres in a total of 19 countries responded, although the majority of these were from France, Germany, Spain and the UK. The overall consensus was that there was an “urgent need for the development of resources for adult CF care” (Madge et al. 2017 p85), which included physical space and appropriately educated staff to facilitate care. Sally’s comment relates more to physical space, although the lack of appropriately educated staff (Lotstein et al. 2005, Peter et al. 2009) was identified in Chapter Two.

Unlike Sally, Jeff was able to make some comparisons between services. Although he did not make a direct comment he alluded to the fact that he was unable to stay with Katie in the adult setting, which he appeared to find difficult when he suggested that “... *I had to take her there [to adult hospital] and leave her there... I had never done that before*”. This made him recognise that “... *going to [named adult hospital] the first time..., it was all a new thing and a learning experience really*”. However, Jeff was a pragmatic individual and he identified that “...*you tend to, you adapt to new things as you find them*”.

It seemed however, that Jeff did not really spend much time at the adult hospital to form any specific opinions as he recognised that his daughter spent limited time there herself:

There are occasions where the ward is full anyway, uhm, and she just goes home then [to manage her own IV therapy]

...she doesn't actually spend much time on the CF unit anyway because a lot of the time she does her own antibiotics at home.

This last statement concurs with the comments Katie made regarding managing her own IV therapy at home with the support of her parents (see section 7.4.2).

In contrast, as Molly had only recently been admitted at the time of the interviews, it is not surprising that Carol was the most vocal of all the parents and she made considerable comparisons between child and adult services, she also made comparisons between the ward staff on the alternative ward and the CF team.

Carol's initial comparisons were linked to the fact that she was unable to stay with Molly in the adult setting as she identified that "...a difficult part for me was taking Molly over and leaving her there" and went on to say that "...you're not allowed to stay in overnight and I know that they are getting older but still, they may like their parents to stay". This again is in line with the early research by Miller et al. (1998) who suggest that young people may wish their parents to stay with them, particularly when they are unwell. As Carol is describing Molly's first admission to adult services and she had been admitted with pneumonia, it may have been appropriate for her mother to stay with her as this could have lessened the anxiety for both of them (Streisand et al. 2001).

Carol then continued her narrative by making comparisons between child and adult services using a drug error that had occurred when Molly was on the alternative ward to highlight her concerns:

The nurses [ward nurses] were good [said with some trepidation]. One nurse did give her too much medication...so that was a bit (pause) a big eye opener...

Every time they were putting Molly's medication in the pot we were going through them to make sure [they were correct]. Never had that problem before [in children's services].

Children's nurses are not infallible and medication administration errors do occur within children's services (Ghaleb et al. 2010, Westbrook et al. 2010), however it is evident that Carol had not experienced this situation until Molly's transition to adult services. It is easy to understand therefore, that this would be of considerable concern for Carol as she appeared to infer that this had happened *because* Molly was in adult services.

Carol also noted that:

Uhm, quite a few times we've found tablets on the floor in her room where they dropped her tablets and hadn't picked them up.

Again, it is easy to understand that a situation such as this would be unlikely to instil confidence in staff in adult services (Wong et al. 2010) especially as Carol noted that again they had not experienced a situation such as this prior to transition.

Carol also had concerns regarding the timing of Molly's medications and identified that they were often late and that they had to ask for them. This she noted was different to children's services as she recalled that *"even if they got busy you never had to ask for anything ever in paed's"*.

However on the alternative ward Carol identified that:

...we had to ask for her nebs... We'd ask for them and sometimes like an hour or so later they still wasn't there, so we had to go and ask again.

I had to ask for her Kalydeco® medication a few times, that's the super drug she's on.

These comments have all been grouped together as they relate to medication administration and clearly caused Carol some concern. Medication management is a considerable part of CF management and when nebulisers are used they are often taken in sequence, sometimes with an hour between each and generally they are administered before physiotherapy sessions (Jones and Helm 2009). Therefore, it is understandable that Carol was concerned when they were delayed as this could have potentially affected the timing of Molly's physiotherapy (Jones and Helm 2009), which would have been important to continue given she had been admitted with pneumonia.

The potential benefits of Kalydeco® (Flume et al. 2012, Kaiser et al. 2012) were noted in Chapter One under section 1.5.3 and Carol's involvement in this drug being used in Wales was highlighted in Chapter Seven. It is not surprising then, that Carol considers this to be a 'super drug' and the fact that the administration of this drug was delayed understandably caused her considerable anxiety. It could also have suggested that the staff on the alternative ward did not fully understand the importance of this medication and what this means to individuals with CF and their families.

Carol identified a range of issues relating to differences in care including *"...sterilising with her port, I don't think that was as good as over the adults...physio's changed as well..."*. Carol did recognise that there were differences in care between the CF team and the staff on the alternative ward as she suggested that the *"...CF team were absolutely fantastic, they were on the*

ball". However, she also identified that "*the nursing staff I think opened our eyes a bit, not the CF nurses, the nurses on the ward*".

Another area of concern for Carol was that Molly had the potential to mix with other individuals who had CF and this was a concern for two reasons. Firstly because Molly may encounter individuals at a more advanced stage of CF and she identified that "*now Molly's gone over to [named adult hospital] uhm, she's started speaking to a few CFs [other patients] and...I think it's opened Molly's eyes a bit more*". Although Carol does not state it specifically, the inference was that she had encountered individuals who were not as well as she was. This is in line with previous research (Russel et al. 1996, Madge and Bryon 2002) and although these studies are dated, the fact that Carol has identified this makes them relevant today.

Carol's second concern was due to the potential for cross infection, particularly when Molly was being managed in adult services when she recognised that, "*uhm, (pause) but yeah, they do mix [in adult hospital] and they are not supposed to*". This appeared to be a very real and valid concern for Carol. This is because within children's services, certain aspects of CF management have almost become a mantra; maintain health, promote optimum growth and development and prevent infection (Doull 2001). Although all three aspects of management are of equal importance, the 'prevent infection' part of the 'mantra' is the most important to parents. This is understandable, as repeated chest infections have the potential to lead to irreparable lung damage, (see section 1.6.1), which causes the greatest level of morbidity and mortality in CF (Badlan 2006, Geller and Rubin 2009, West and Mogayzel 2016). Consequently, within children's services, children and young people are discouraged from socialising within the ward environment, 'segregation' becomes a normal part of their lives and socialisation of individuals with CF has "almost vanished" (Tuchman et al. 2010 p 570).

However, Carol's concerns are reinforced when she identified that:

I know quite a few people in [adult hospital] said to Molly 'oh we do mix, we're not supposed to but we do mix, they [the staff] don't like it, we get told off'. But they do, they go out in the car and that together.

It is clear from this discussion that although Carol is only relating what she believes happens in the adult setting, her concerns are not unique. In a study undertaken by West and Mogayzel (2016), being exposed to infection, was the second highest concern parents had prior to and after transition. Although this study was undertaken in the USA, Carol's comments highlight that these results are not country specific and as such, it is appropriate to include it in this thesis. Additionally, this situation clearly causes Carol concern and has the potential to inhibit the formation of a trusting relationship with staff in the adult setting.

9.5.2: Forming Relationships with Staff in the Adult Setting

In childhood and early adolescence young people rely on their parents to manage their CF care for them (Tuchman et al. 2010) and in children's services, parents are encouraged to participate in the care of their hospitalised child (Callery 1997, Shields and Nixon 1998, Lugasi et al. 2010). As a consequence, parents often form close bonds with staff in children's services and due to the increasing focus on patient focused care in adult services (Kirk 2008) family involvement is limited (Iles and Lowton 2010, Reed-Knight et al. 2014). This has the potential to inhibit the development of trusting relationships between parents and staff. Although forming relationships with staff in the adult setting was not a considerable focus within the parent's interviews, it was mentioned therefore, it was an important issue to raise within this discussion chapter.

Jenny did not discuss her own involvement with staff in the adult setting, but instead she suggested that her son Tom had not really been able to form a relationship with staff in adult services:

I think looking back, the trouble was, because he didn't go [transition] until he literally had to go to uni, they [the adult staff] didn't get to know him and he didn't get to know them,

...the nurses too in the adult service are lovely, they are just nowhere near as involved. And I don't feel like they know Tom... whereas, I guess he grew up with [named CF nurses] (pause) and they knew him so well...

Jenny recognised that although Tom was being cared for, she implied that things were 'not the same' and that the same level of bond had not been achieved between Tom and staff in adult services as he had been able to make with the staff in children's services.

It's hard isn't it, ...you know they are looking after him and they are keeping a close eye and they are you know, having him back every week (pause) uhm and yes, he wouldn't phone them up for anything like we would phone [named CF paediatric nurse] up.

This is a slightly concerning statement as it identifies that Tom may not contact the adult CF team if the need arose, and could be a sign that he is disengaging with service provision (Viner 2008).

Sally did not really comment on her relationship with staff in the adult setting other than to identify that ... *"I was accepted [by the staff] while I was there as well"* [adult services], although in relation to overall communication, she suggested that... *"I don't think the communication is as good as it used to be"*.

Like Jenny, Carol discussed relationships with staff in the same context, in that it related to their understanding of Molly and the way they managed her and she identified that:

Uhm, she's a bit needle phobic as well. Uhm so they [staff in adult setting] were just coming in her room with a needle and saying 'right I'm just going to do you bloods'.

Although Carol did not state it outright, she did appear to be inferring that the reason this situation had occurred was that the staff did not know Molly well enough to understand that she was actually needle phobic. However, she then added that *"they were very friendly over there in [named adult hospital] but we don't know them like we've, like with paediatric"*.

The parents who made comments in this section all appeared to be equating providing 'good care' with knowing their young person well. This is supported by West and Mogayzel (2016) when they identify that the longer young people spend in children's services, the greater the emotional ties they have with the staff there. This becomes a difficult bond to break and it could be argued that staff in the adult setting will never be able to form the same close bond with young people as children's nurses have. This could be for reasons already identified by several participants in this study, (Karen, Katie, Jeff) that as they get older, young people tend to spend less and less time in hospital as they manage their own care at home.

However, the differences between FCC and patient focused care or self-advocacy need to be highlighted here again. In children's services, parents are encouraged to participate in their child / young person's care, they become familiar with the service, procedures and as West and Mogazel (2016) point out, with the staff. In adult services, the expectations are different and focus more on self-reliance, self-advocacy and parents often (as evidenced in this study) feel excluded. Healthcare professionals cannot escape the fact that child and adult services are different, the challenge therefore is to adequately prepare young people (and parents) for these differences, which I would argue cannot be achieved by using the FCC model.

9.5.3: Staffing Issues

It was evident that some parents had tried to form a relationship with staff in the adult setting, but this was variable and only Sally and Carol gave this any prominence within their discussion. It is possible that Jenny, being a nurse herself, did not view issues around staffing any differently to what she was used to within her own practice and although Jeff did make some comments regarding staffing these were very politically based and related more to the staffing of a new CF Unit, which had not opened due to lack of funding, therefore they have not been included in this section.

Sally identified that she had seen changes in the staff in the adult setting and as highlighted in the following comments, she wondered why that had occurred:

...when you see that one or two, well you know, probably one or two, a handful of the staff really, now are absolutely, well, one hopes that they are tired rather than complacent.

The last two years there uhm the (pause) you know it sounds like I'm putting people down uhm, its changed – is that because of the pressure on them?

...I think there are lots of weary people with the pressures that they have on them, put it that way...but only by a few, that has to be said and as I said before maybe it's just pure exhaustion too much asked of them I don't know, I don't know (pause).

It is evident from Sally's comments that although she recognises these changes, and considers the possibility that some staff are complacent, overall, she believes the potential reasons are, that the staff are under pressure and tired.

Carol agrees with this assessment although she relates her comments back to the intruder in Molly's room and the medication error to provide examples.

Oh, (pause) it was scary to know, I'm thinking she was in hospital safe, she was safe, he wasn't doing no harm, it's just he didn't know where he was and to be fair to the nurses, they are busy and I understand that they can't watch him 24/7.

You know over there in adults they were absolutely rushed off their feet and you had this wanderer as well going around and it was like, it was frustrating for us because we had to ask for the medication whereas before [children's services] we always had them in our fridge and we could do them as and when.

Linking her comments to the business of the staff and the medication error are actually appropriate, particularly as Ghaleb et al. (2010) highlight that the more nurses are interrupted during the administration of medication, the more likelihood there is that errors can occur. Given that Carol identified that the staff were “*rushed off their feet*” it is possible that a distraction during the administration of Molly's medication could have led to her medication error. However, far from criticising and blaming the nursing staff or giving any serious conviction to labelling nurses as “impersonal” or “unfriendly” (Viner 2003 p210) the participants in this study recognised the difficulties nursing staff faced and in general, they supported them. However, it could be suggested that by their continued support, it is enabling the issues they have identified as being of concern, to go unnoticed and therefore not addressed.

9.6: Family Issues

CF does not only affect the person who has this condition, it also affects the rest of the family to varying degrees. For parents, this starts at diagnosis, when for some, it is the first realisation that they are both carriers of a CF gene (UK Cystic Fibrosis Registry 2016) and it is natural this this would also affect grandparents. Following diagnosis, many parents actually move through the five stages of grief (Kübler-Ross 1997) as they grieve for the ‘loss’ of a normal child (Harrop 2007). This grief process has the potential to increase stress and anxiety, as well as cause physical and mental health issues (Streisand et al. 2001). The latter being emphasised by Sally's disclosure during her interview of agoraphobia.

Siblings are also affected by having a brother or a sister with CF and can experience negative emotions such as jealousy, increased anxiety, resentment,

guilt and low self-esteem, or have a more positive response by being closer to, and protective of the affected sibling (Williams et al. 2009). With regard to the parental participants in this study, Jenny and Carol both had more than one child, but Sally and Jeff only had Katie. Overall, the parents tended to focus on their own personal experiences and the siblings were only mentioned briefly.

9.6.1: A Sense of Loss

As individuals the majority of the parental participants experienced a sense of loss. For Jenny this focused around leaving the ‘family’ of children’s services and Tom’s transition. In relation to leaving children’s services, Jenny reflected back on her relationship with the staff in the children’s setting.

I’ve missed [named two CF nurses] desperately, desperately, but you know I see them around the hospital all the time (sounds wistful) and uhm, but it is strange, it is strange after being so involved in a service.

I went to his first appointment [adult clinic] and, and, he never wanted me to go again (said with some sadness).

It is clear that Jenny has experienced a sense of loss with regard to the support she received from the CF specialist nurses in children’s services and there is no easy answer to try to find a way to resolve this. Parents tend to form a close bond with staff in children’s services and breaking this bond is one of the main concerns parents have regarding transition (West and Mogayzel 2016). This seems to have been compounded for Jenny, when coupled with this, Tom decided after his first outpatient appointment that he did not want her to go with him anymore.

Sally related her experience of loss to the actual transition process and she identified that “*I felt redundant if I am honest*” and although Sally did not visit Katie when she was hospitalised, she was heavily involved with her care at home. As young people are encouraged to be more self-reliant prior to and after transition (van Staa et al. 2011) it is possible that this translated to Katie being more assertive regarding managing her own care at home, which caused Sally to feel left out and “*redundant*”.

Jeff only made two brief comments in relation to a sense of loss. The first focused on when Katie moved out of home when he identified that:

[when Katie went to university] *then we found that our sort of grasp on her treatment and our supervision was slowly starting to slip away.*

Jeff also suggested that not being involved in Katie's care, left them somewhat at a loss when he recognised that:

We'd be here [at home] at 9 / 10 o'clock when we should have been doing it [physiotherapy] looking at each other and wondering what do we do now type of thing.

Carol also found transition difficult and suggested that. *"I struggle with it to be honest with you. I keep it to myself..."*

It is understandable that parents feel a sense of loss, (see section 1.7) when they are no longer spending the majority of their time caring for their young person, as their role shifts from carer to support person and this may be difficult for them to come to terms with (van Staa et al. 2011). It is important therefore, that staff within both the child and adult settings recognise the potential difficulties that some parents face and work together to make the transition for parents as well as young people, easier to manage (Iles and Lowton 2010, van Staa et al. 2011, West and Mogayzel 2016), as parents clearly have a role to play in the ongoing support of their young person.

9.6.2: On-going Support and Advocacy

There has always been an expectation that as young people with CF get older they will take on more responsibility for managing their own care (Schmidt et al. 2003, Langton Hower and Tyrell 2008, van Staa et al. 2011, West and Mogayzel 2016). This includes being responsible for their overall management regime and manoeuvring the healthcare system successfully (Doull and Evans. 2012). They also need to be able to manage clinic appointments, interact with the multidisciplinary team to ensure that their concerns are heard and that their input is acknowledged. However, to enable them to do this, the role of the parent needs to change as they need to take a step back and change from being a carer to a supporter (van Staa et al. 2011, West and Mogayzel 2016). However, this is not always easy for parents to achieve and Jenny highlights how easy it is to slip back into the 'old ways'. Jenny had been discussing Tom's return home from university when she noted that *"and now that he's home he's dependent on me because that's the way isn't it?"* When she said this she shrugged her shoulders suggesting the inevitability of the situation in that even though Tom was capable

of managing his own care, he relied on his mother to take over when he came home. Alternatively, this could be a form of 'learned helplessness' as in, if Jenny always managed Tom's care before he moved out, it would be natural to him to revert back to that system when he returned home.

In relation to BMT the neutral zone is the 'in between' time where changes have occurred, but they may not be completely functional (Bridges 2009). With regard to this study on transition from child to adult services, this could relate to the period of time when parents are still involved, or feel the need to be still involved with the management of their son / daughter. It is during the neutral zone that psychological readjustments have to be made, to enable the acceptance of the 'new ways' to occur. With regard to the change from parental to self-management, this needs to occur from the perspective of both the young person and their parents. Reaching the level whereby young people increase their level of self-management and parents reduce the level of their care, would enable both young people and their parents to move from the neutral zone of BMT to new beginnings (Bridges 2009).

If the transition process is managed appropriately, young people should be fully engaged with the concept of self-care prior to moving to adult services (Tuchman et al. 2010). Although it may have been difficult for them, all of the parents in the study recognised the need to take a step back and in general, the young people appeared to be happy to take on this responsibility. Therefore, it was disappointing to note that two of the parents in this study identified situations where their young people were not listened to, and as such, their ability to self-manage their own condition was compromised. The first situation related to Jenny's son Tom and the second to Sally's daughter Katie. On each occasion, prior to parental intervention, although both Tom and Katie had raised their concerns with healthcare professionals, these had not been addressed and as a consequence both of their mothers had to step in and advocate for them.

In Jenny's account of her son Tom's situation, she placed more of an emphasis on *why* she became involved as opposed to *how* she became involved. This followed on from her previous comment regarding Tom returning home from university and resuming responsibility for his care as she recognised that since Tom had been unwell, she had started going to clinic with him again:

And, it's only been now in the last couple of months that I've started to go again [to clinic]. I've been a few times since he's been poorly because he's wanted me to go.

However Jenny then identified that it was not just because Tom was unwell that he wanted her to attend clinic with him:

*He asked me to go... he came home from one appointment and said 'mum they are just not listening to me'...So, I went with him and I know exactly what he means, this consultant was just (pause) very pleasant (smiles), but really didn't listen! **Really** (with emphasis) didn't listen to him..."*

Jenny also recognised that this was not the only time that Tom had been in a situation where he had not been listened to as she identified that:

I left work early one day because it was the consultants round... and, Tom wanted me to be there and I, the overwhelming kind of feeling was you need to look after yourself better (stated in angry tone) and that was so unjustified.

Sally identified that she had no issues with speaking up to advocate for Katie and she suggested this was because:

We've always had contact and if uhm perhaps if she's so poorly that she can't voice things herself that needs to be voiced, I will ask... Uhm maybe that's because we make ourselves known. I don't mean that in an aggressive way uhm and we are not pushy.

However she then went onto explain that:

There was one example where she said 'Mum, would you please'...that was when she asked me to speak out for her...and uhm it was quite a surprise...and I very much knew that there was something not quite right and she was not being listened to...when she asked, rather than me stepping in, that was about when she was 25 about 8 years ago...she had never needed it [speaking up for her] before, never asked and it had to be done because uhm yes, let's just put it that way...

In contrast to Jenny's account, although Sally briefly identified *how* she had become involved, for her the discussion related more to the fact that she had *needed* to intervene. Sally, clearly thought, that there should have been no need for her to do this, especially at the age Katie was when this incident occurred.

If there is an expectation that young people, and in Katie's situation young adults, with CF should be managing their own care (Patton et al. 2003, van Staa et al. 2011, West and Mogazygel 2016), not listening to them when they do raise

concerns would be difficult for them to contend with. Furthermore, for the staff to act after parents had intervened appears to *reinforce* the fact that the young people were not being listened to, and this sends out conflicting messages to the individuals concerned; you are old enough to take care of yourself, but if you really need something your parent's will have to ask. In situations such as this where a young person may be going through the 'testing boundaries' phase of adolescent development, giving them cause to believe that they are not being listened to, could lead to issues surrounding non concordance / compliance with management (Langton Hewer and Tyrell 2008).

However, in Katie's situation, her mother's intervention was needed when she was in her late twenties, which actually negates issues surrounding adolescent development, but it does raise another potentially worrying hypothesis. At this point Katie could have been considered to be an expert patient in her own right (Wilson et al. 2006, Taylor and Bury 2007). However, CF is still perceived by many to be a childhood condition ergo, everyone with CF is a child and can be treated as such. *If* this were to be the case, it has considerable implications for the management of young people and young adults, as infantilising them in this way, could have the potential to compromise their relationships with healthcare providers and ultimately have a detrimental effect on their overall health and well-being.

Parents also need to manoeuvre through the BMT neutral zone to enable them to reach new beginnings as this is the 'in between time' when they are stepping back from being the full time manager of their son / daughter's care. Consequently, transition can be a difficult time for parents with authors such as Viner (2003) suggesting that some parents may even "sabotage" (p2685) their son / daughter's transition, whilst others have suggested that parents are resistant to change (Hink and Schellhase 2006). One reason that has always been put forward for this, is that parents fear a reduced input into their young person's care (Russell et al. 1996, Boyle et al. 2001), which has been related to a loss of parental control, exclusion from the adult setting (Hink and Schellhase 2006, Reed-Knight et al. 2014,) and a fear of 'letting go' (Westwood, et al. 1999). This is why West and Mogayzel (2016) suggest that healthcare professionals should remember that parents are also undergoing a transition. However, a fear of letting go and relinquishing care was not found to be the case within this current study.

From a parental perspective, all of the participants in this study recognised that transition was inevitable and that when the timing was right, it *should* happen. They also acknowledged that young people needed to be able to manage their own care. Although several studies (Westwood et al. 1999, Boyle et al. 2001, Flume et al. 2001) have suggested that parents have major concerns regarding their adolescent's ability to manage their own CF care, this again did not appear to be evident in this current study. The parents in this study *were* anxious that they would not have such a great input into the young person's care but given their comments regarding drug errors, late medications, infection control, increased socialisation between patients with CF, and adult healthcare staff not responding to the needs of the young people, it appeared that the parents in this study were more concerned that without their continued involvement and monitoring, the health of their young people would be compromised. Part of the reason for this anxiety was an apparent lack of trust in the adult system, some of which was based on their own experiences or due to a lack of information related to the procedures and processes within the adult setting.

9.6.3: The Effects of CF on the Family

Although the parents did not labour the point they all identified that their son/daughter having CF had impacted on the family overall. Jenny used the example of her son moving out to university and then returning home on a full time basis at the end of his course as an example of how Tom having CF affected her and her daughter.

...you don't realise how much, I hate to say it, but it's easier when he went away.

You kind of get out of living with CF a little bit, of the roller coaster of it and then he'd come home and he'd be around and suddenly you'd be plummeted back into that roller coaster you had almost forgotten about.

Yes, and it has such a huge effect on the whole family...it's hugely time consuming, hugely and him being back has such a huge effect on me and my daughter, it really has.

Jenny's comments were honest and open, but it was clear that she was experiencing some level of guilt, possibly just because she had actually spoken the words out loud.

Sally who, because of her previous mental health issues, was possibly the parent who had been most affected by a diagnosis of CF in the family, summed up the impact of living with CF for her, when she stated:

...I don't know about acceptance [living with CF] you know, it's like a little knife going into you each time – it never gets any easier.

Interestingly, throughout the trio of family interviews (Sally, Jeff and Katie), Sally was the only person to mention Katie's husband. She did this twice, but on this occasion it was in the context of family involvement, when she recounted a conversation they had, just after Katie's wedding.

Yes, we talk openly and I said [to son-in-law] 'oh you know you're a great man and he said 'what do you mean' and...(pause) if you will allow it, uhm there's going to be much more involvement from Jeff and I in your marriage than perhaps there would be for others and uhm he just put his arm around me and he said 'and I wouldn't expect it any different'.

This conversation highlights the continued involvement of parents of young people with CF well into their adult lives, particularly where they still help out with managing care and the way this also has the potential to impact on 'new' family members.

Jeff made several comments regarding the impact CF had on him as an individual and on his marriage. Jeff who seemed to be a pragmatic individual had clearly found Katie's diagnosis of CF difficult to comprehend, as he identified that, *"I wasn't prepared for it [diagnosis]. Although even if you are prepared, I don't think it helps...but it did, it shook me"*.

Prior to the interview starting, Jeff had mentioned that he and Sally had been married for over 40 years, so it is not clear whether during the interview, he was alluding to any previous marital disharmony within his own marriage when he made the following comment, *"I don't know whether there's any stats on it but I would imagine there's been quite a number of divorces when CF is involved"*. Although Jeff was not specifically referring to himself when he mentioned divorce, it is clear that he recognised the increased stress having a young person with CF places on parents (Streisand et al. 2001, Cousino and Hazen 2013, Heath et al. 2016) and in his reasoning, this could lead to divorce.

Jeff then went onto make a more personal comment when he identified that “...one thing we did decide that with Katie having CF, we decided not to have any more children because of that”. There was considerable sadness in Jeff’s voice when he said this, which led me to believe that although he thought this was the right thing to do, it may not have been what he originally wanted. However the decision is understandable, as for parents who carry the CF gene, for each pregnancy there is a 1:4 chance of having a baby born with CF (James et al. 2002, Jackson and Pencharz 2003) and some parents are not prepared to take this risk.

Carol’s comments focused on what she had previously termed as the ‘wonder drug’ Kalydeco®, as since commencing this medication, Molly had been well and her first admission following transition actually related to pneumonia and not an exacerbation of CF. However, although Carol recognised this, it was apparent that the seed of doubt was always at the back of her mind, as she explained:

But, there is always that little doubt, thinking of it [Kalydeco®], does it work, will it work, will it work forever? Uhm (pause), so yeah, I am scared of the future.

Therefore, to make sure that she stayed well, Carol also identified that she needed to make sure that Molly always followed her management regime and that as a consequence she felt that “...I’m probably a nag to her (laughs)”. Although Carol laughed as she said this, making sure that Molly stayed relatively well was a serious focus of her life and monitoring whether or not a young person is adhering to their care regime by parents is common where a chronic illness is present (Heath et al. 2016).

Carol also identified the difficulties she had surrounding the care of her other children when Molly was unwell, as she explained that, “...they [other children] would have to go down my mum’s for two weeks” [when Molly was admitted] and that, “I found it hard trying to split myself three ways... trying to make sure that the other two were alright as well...”

Despite all these issues having the potential to increase parental stress (Streisand et al. 2001, Cousino and Hazen 2013, Heath et al. 2016), the parents in this study also demonstrated a more positive attitude to living with CF.

Jenny identified how she approached the management of CF and explained that she had not allowed it to be a dominant factor within the family as she explained:

...we've never let CF dominate us. We've always been very strong in that...so he never really became hospitalised, we were never a family that lived in the hospital and I think that makes a big difference...we've done IV drugs everywhere...and yeah he has just carried on.

Jenny's 'no nonsense' approach to CF could be attributed to the fact that she was a registered nurse, but I also experienced this same sort of attitude with all of the parents who participated in this study. It was also evident that Jenny was proud of Tom's achievements when she identified that, *"...when he first went to uni I was proud of him (said with pride and forcefulness), I was so proud of him that he could do it all for himself"*.

Sally's comment was brief, but suggested that her positivity was rooted in the fact she believed that, *"I think we're lucky in as much as we are a family that can talk..."*

Jeff clearly tried to maintain a positive attitude and was optimistic of future improvement in management. He also suggested that this was something that he tried instilling in Katie.

We've always tried to instil in her [Katie] to look after herself because things will get better and hopefully we are getting to that point.

Although Carol had previously identified some fears regarding the continued effectiveness of Kalydeco®, she also suggested that it did bring hope for the future as she recognised that, *"before she was on that [Kalydeco®] I constantly worried about the future, really, really scared of the future"* Consequently, although Carol still does have some concerns, she does infer that overall the future for Molly looks more positive.

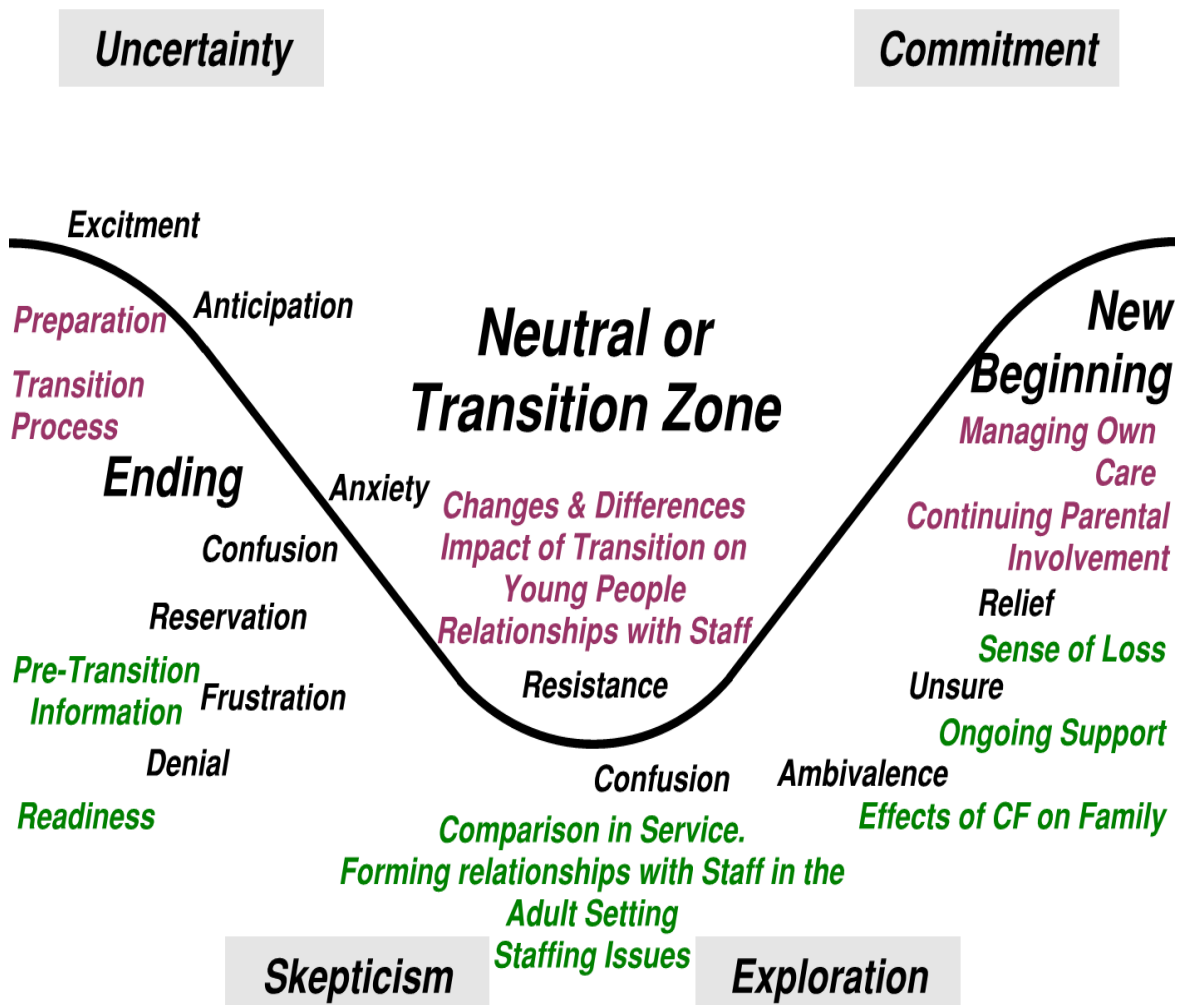
All of the parents in this study demonstrated some level of hope and optimism for the future and this could help them to cope with and adjust to the transition of their young person to adult services (Griggs and Walker 2016). However, I believe that the overall approach to CF by the parents in this study can be summed up in a comment Jeff made:

It was just a case of playing with the cards you were dealt I guess.

9.7: The Bridges Model and Transition from Child to Adult Services

The appropriateness of using BMT and the methodological ‘fit’ this had with IPA has already been identified. BMT was designed to facilitate transition/s in a variety of situations and thus lends itself to the healthcare setting. The way in which BMT applied to the superordinate and subordinate themes for both young people and parents were identified in Tables 21 and 22, what is needed now is to apply BMT to this current study. The following illustration identifies the way in which the themes that were discussed within this chapter also relate to BMT.

Figure 3: Bridges Model Applied to Transition from Child to Adult Services for Young People and Parents



In this illustration, the three phases (ending, neutral zone and new beginning) of transition are identified. The line running through the model, represents the 'roller coaster of change' that some young people and their parents can experience during transition and the four main domains of uncertainty, scepticism, exploration and commitment are part of the roller coaster ride. Within each of these areas, Bridges (2015) identifies the feelings that can be experienced by the individual/s undergoing any form of transition. These basic aspects of the BMT are depicted in black type and the coloured type depicts where the young people (purple) and parental (green) subordinate themes from this research sit within the model.

9.8 Reflection

Undertaking this research has enabled me to fulfil an ambition that was first conceptualised in the late 1980s when I worked on a specialised adolescent unit in Melbourne, Australia, where a large proportion of our clientele were young people with CF. I always realised that I wanted to combine my interests in adolescence, CF and transition and work this into a research project. However, it was not until I returned to Wales that I was able to do this, although it has been undertaken over a longer period than first anticipated, which has affected certain areas of this work.

I suppose if I am being honest with myself, the issues with this research started right at the beginning of my candidature. I had been out of the country for a long time, I had no local contacts, medical and nursing staff I had previously known as colleagues had moved on and due to my role, I had limited access to the gatekeepers within the health care setting. However, contacts were made and preliminary discussions indicated that this was a worthwhile project. Full of enthusiasm and optimism, I subsequently enrolled in October 2007.

I have been asked several times why I enrolled in a Professional Doctorate and not a conventional PhD. My answer to this has always been twofold; firstly, that having undertaken a Masters of Nursing (Research) based on a PhD format, I felt that I had not had any real grounding in research philosophies and methodologies as a whole, so the taught component of the 'Prof. Doc.' would resolve this. Secondly, that it would be quicker. I would do the taught component in two years and then take two, perhaps two and a half years for the research component. Looking back, I cannot believe that I said or even thought this,

because either I had injected myself with an overdose of optimism, or I was on the verge of insanity. Either way, that is what I said and thought at the time, but that little phrase 'would be quicker' has come back to haunt me time and time again.

Recruitment was lengthy as it took over three years to recruit participants. I found this very hard to accept at the time, surely young people wanted to tell me about their experiences. An additional six months of negotiation with the Adult CF Team left me feeling frustrated and dejected. Consequently, if I were to undertake this study again, I would give more thought to recruitment and how I would 'sell' the study to potential participants. Although I was eager to 'get on with it', the saying that hindsight is a curse, is very true.

The literature review was first started in 2014. Consequently, it has been necessary to revisit the literature at several periods throughout my candidature. Although this has made it feel like a never-ending task, it has been beneficial, as it has given me the opportunity to seek out new articles and maintain my focus on the topic as a whole.

It was perhaps problematic that I did not start out with the intent of using IPA, if I had, I would have had a better understanding of this from the outset and not learned about it as I went along. This made me feel at times as though I was always on the back foot and trying to play catch up with myself. It may also have helped me to focus on being more of a researcher, which I am trying to be and less of a nurse, which I still consider myself to be. I believe that this influenced the way I conducted the interviews, for example, Sally's need to tell her story about Katie's diagnosis dominated her interview and the information she provided regarded transition was minimal. At the time, I do not think I fully realised that this was happening. I believe that the empathetic nurse in me 'kicked in' and it was only when listening to the tapes that I realised that the interview had been manipulated to cover the topic Sally wanted to talk about and not what I had initially asked her about. I remember feeling disappointed when I listened to the recording as I felt that I had wasted one of my precious interview slots. However, Sally's description of her daughter's diagnosis was heart rending and I became quite emotional when I listened to the recording, which did surprise me somewhat at the time, as I do not give way to my emotions easily.

Additionally, I found Ben's interview particularly challenging. Ben was my second interview and although he had willingly participated, his 'condition' was that it was undertaken via the telephone. I was apprehensive about this from the outset, but as it was phone interview or no interview, I pragmatically opted for the phone interview. Throughout the interview, Ben appeared to be a little distracted. I am not sure why this was the case; possibly because he was a young man and it just related to his overall communication skills, or it may have been because it was via telephone and I was unable to make face to face and eye contact. Generally, I do not have any problems communicating with young men, I have two sons myself and when they were adolescents, their friends were constant visitors to our house, especially for pizza/DVD nights and 'sleep overs'. I have never had a problem communicating with any of them and I was beginning to feel that with Ben I was failing in my communication skills. During the long pauses within the interview, I kept wondering where I was going wrong – why was I not getting to him? Whatever the reason, Ben's interview was like the proverbial 'pulling teeth' and I failed to draw him out. His responses were stilted and to the point, and the only time he became animated was when he was discussing his sporting activities. Given that I have considerable experience working with young people in the acute, community and voluntary sectors, I found this disappointing and somewhat discouraging, but fortunately, this was an isolated episode in comparison to the other interviews.

I did find the linguistics analysis within the IPA process challenging and it took me several attempts to find something that I felt was worthy of discussion. Initially I focused on metaphors and analogies and as there were not many of these used by either the young people or parents, I was becoming exasperated. I knew I was missing something, but I could not seem to work out what it was that I was missing. I had several discussions with my supervisors regarding this and I feel that this was one of the areas where I needed the most guidance and support. I was encouraged to keep reviewing the transcripts and although I found this frustrating at the time, it was only by reading and re reading the transcripts that the medicalisation of the participant's language became more apparent. Where metaphors were used, I think the one I found most interesting was Sally's describing Katie's transition as making her feel redundant. I had never viewed transition for parents in that way before, but it does make sense, particularly as anecdotally many mothers of young people who have CF do not work outside the home.

This Doctoral research study / thesis, has been a lengthy process and there have been times when I felt that I would never accomplish what I set out to do. There have been many difficulties including a bereavement, a diagnosis of arthritis that finally led to a total hip replacement and an extended period of sick leave. Friends and colleagues have asked me how I have been able to continue and what has kept me motivated. My usual comment was that I was too 'bloody minded' to give in, but there was more to it than that. I have three (adult) children who have all gone on to undertake higher degrees (two Masters and one PhD) in very different areas of study and they have all told me that I have always inspired and motivated them to undertake university studies. My husband of 42 years has supported me and encouraged me every step of my journey and when I did think of 'throwing in the towel', I thought of my husband and children and told myself that I would be letting them all down if I did not see this through to the absolute end.

Furthermore, I interviewed eight participants for this study, the majority of whom welcomed me into their homes and shared their experiences with me. Some of these experiences were very personal and emotive and I was privileged that they felt that they could share their stories with me. However, the participants shared their stories with me because I was undertaking research and that the findings of that research would be shared with a wider healthcare community with the aim of improving the transition experience for other young people. Therefore, it would have been disrespectful and unethical to have gathered the data and then not done anything purposeful with it.

9.9: Chapter Summary

Within this chapter the superordinate and subordinate themes were used to structure discussion surrounding the experiences of the young people and the parents who participated in this study. These themes were discussed individually and placed within the existing literature as well as relating the process to the three phases of BMT. There were several interesting issues identified within this chapter including:

- The provision of information to young people and parents was inconsistent and sometimes poorly timed, with limited key facts regarding what to expect in adult services.

- Parents were particularly concerned regarding the potential for cross infection related to increased socialisation in the adult setting.
- Parents often feel a sense of loss following transition.
- Contrary to previous research, the parents in this study did not object to relinquishing care, their main concern was that if they were not involved, they could not be reassured that their son / daughter's health would be monitored appropriately.
- Regardless of the age of the young person and the length of time since transition there are occasions where parents need to step in and advocate for them and young people value the continued input of their parents after transition.
- The longer young people are in children's services, the greater the emotional ties they have with the staff there.
- Healthcare professional need to be aware that parents are also undergoing a transition period.

However the main key findings from this research are that;

- There are tensions between self-advocacy and co-production (the adult model of care) and family centred care (the children's model of care).
- The 'normal' developmental aspects of impending adulthood and a perceived sense of loss (compounded by FCC) in turn risks the eventuality of;
- An ineffective 'cliff edge' transition process

The next chapter, the conclusion, will draw this thesis to a close and make recommendations for practice and future research.

Chapter Ten

Conclusion and Recommendations

10.0: Introduction

The aim of this thesis was to explore the experiences of young people with cystic fibrosis (CF) and parents who had made the transition from children's services to the adult CF healthcare services, which are located in a large healthcare provider in Wales. To fulfil this aim, a qualitative research study was undertaken to seek the views of four young people and four parents in relation to their experiences of the transition process. Although the original intention was only to undertake research with young people, a chance discussion with a mother, guided me towards including parents within this study and this I believe, provided an added depth to the findings and subsequent discussion.

10.1: Answering the Research Question

The primary research question for this study was:

What are the lived experiences of young people and parents following transition from child to adult CF services in Wales?

The primary research outcome for this study was to:

Successfully articulate the lived experiences and the sense making of young people and parents following the transition from children's to adult CF services in Wales.

I believe that I have been able to answer the research question in that, by undertaking in-depth interviews with both the young people and the parents, it provided them with the opportunity to share their experiences of transition. However, it is recognised that some of the interviews elicited more information than others. For example, Ben was particularly difficult to engage and Sally was difficult to keep focused as she spent a considerable amount of time relating her experience of Katie's diagnosis. Additionally, it is recognised that although some 'out of area' participants were recruited, the majority of participants resided in close proximity to both the child and adult CF services. Therefore, the experiences of individuals living in a wider geographical area across Wales were not identified within this study.

The early part of this thesis provided a background to the study and an overview of the main operational definitions. The intention of this discussion was to place adolescence, CF and transition in context and focus it within the thesis as a

whole. Following this, a critique of the literature surrounding the main themes of transition was presented and this highlighted the lack of research in relation to CF and transition, specifically in Wales, thereby supporting the need for research to be undertaken in this area.

The conceptual framework used for this research, was the BMT (Bridges 2009) and an IPA approach was used to analyse the data (Smith et al. 1999) gathered from the in-depth interviews to provide a descriptive, ideographic, conceptual and linguistic perspective on the data. The process of undertaking this was supported with tables, which identified the superordinate and subordinate themes, which were then taken forward for further discussion. In addition to this, a 'divergent theme', or a divergent theme (Smith et al. 2009) that stood apart from the rest of the superordinate and subordinate themes was also identified. The results from the study have aided in answering the main research question.

Young people and their parents need information to facilitate a smooth transition to adult services. However, the provision of information prior to transition was variable, this even included where young people had been transitioned from the same location to adult services and this lack of information tended to heighten their anxiety. Information was classified by the participants as written, verbal and also visits accompanied by children's nurses to the adult setting. In general the younger participants reported a more positive than negative transition experience and overall expected very little from the transition process.

The majority of young people felt they were able to manage their own care appropriately, although only Karen identified that she had felt 'self-sufficient' prior to transitioning. However, all of the young people acknowledged and appreciated the ongoing support of their parents.

Changes in management styles between child and adult services were noted and it is evident that this did present some difficulties. It was recognised that this could be related to the prolonged use of family centred care (FCC) when caring for young people in children's services. Although FCC is considered to be the optimal standard of care for children (Ahmann 1998) this does not necessarily make it appropriate for young people. FCC also has the potential to foster a prolonged dependence on healthcare staff in children's services by young people and parents. This dependence increases the longer young people and parents

spend in children's services as the emotional ties become greater (West and Mogazel 2016). Transition needs to be planned and managed appropriately otherwise, an unintended consequence of FCC is that it has the potential to foster a 'cliff edge' form of transition for both young people and parents, whereby they are 'dropped' or 'pushed' from one service to another. Healthcare professionals in children's services need to adequately prepare young people (and parents) for the changes and differences they will encounter when they move to adult services in an effort to facilitate a smooth transition. The challenge in facilitating this I would argue, is hindered by the use of FCC in the care of young people.

In an ideal world, all young people would be given the opportunity to be cared for on an adolescent / young people's ward (Hutton 2002, 2005, 2007, 2010 Viner 2001b, 2007) however, given the current fiscal climate within health services, particularly within Wales this is unlikely to occur within the near future. Therefore, it is important to consider an alternative model of care or management framework to use with young people. This would assist in preparing young people and parents to disengage with children's services in preparation for continued healthcare provision in adult services.

To facilitate this a hybrid form of FCC / self-care could be used with young people prior to transition. This could also be used within the adult setting immediately post transition and as part of this *negotiation* between staff, young people and parents should take place to enable parents to continue to have a direct input into their young person's care, if this is required by the young person and their parents. This would potentially make the differences between child and adult services less obvious and help to prevent the sudden and abrupt 'cliff edge' transition.

In relation to moving 'out of area' where participants had moved from DGHs to the adult CF centre, the increased level of specialist care, the range of services and increased facilities, were recognised. However, for some participants moving to a different hospital and 'out of area' to a different Health Trust was problematic, with one participant moving home to be closer to adult services. Although it is recognised that the optimum way to manage CF is from specialist centres by multi-disciplinary teams (Flume et al. 2001, Doull and Evans 2012), this does not always happen as prior to transition, some young people are managed in DGHs,

(UK Cystic Fibrosis Registry 2016) as evidenced in this study by Ben and Katie's experiences. It is unclear therefore, why, if prior to transition CF can be managed effectively in co-partnership between DGHs and the CF centres for children and young people, the same model cannot be followed for adults who wish to stay closer to home. This would have the potential to limit disruption for young people and parents.

From a parental perspective, the impact that CF had on the family as a whole was acknowledged and one parent in particular identified the roller coaster experience of living with someone who had CF. In general however, the parents in this study had not allowed CF to be a dominant focus of family life, and although CF management was noted to be disruptive, they did their best to ensure that CF fitted into family life as opposed to fitting family life around CF.

The majority of parents had found transition difficult in some way. They missed the involvement in their young person's management and some felt at a loss, not knowing what to do with their time. Although one mother recognised that when her son returned to live at home this had been equally as problematic as he had automatically reverted to being dependent on her again.

Monitoring their young person's care was of particular importance to the parents as they had noted differences in the level of care between child and adult services. One major concern for parents was the apparent increased socialisation between individuals with CF in the adult setting and the potential increased risk of cross infection. Additionally, when young people were not admitted to the CF ward, the parents identified considerable differences in what they viewed as different standards of care between 'ward staff' and the CF team.

Parents also recognised what they perceived to be the pressures that nursing staff within the adult setting were working under and that as such, it was felt that some staff had become "*tired and complacent*". Although they did not apportion any blame to the nursing staff, the parents did recognise that this potentially impacted on the overall care that their young person received.

10.2: Implications for Practice

In summary, transition is a potentially difficult process for young people and their parents. However, for young people in this study they conveyed more positive

than negative experiences of transition. Parents recognised the inevitability of and need for transition although they did express concerns that their young person's condition might deteriorate without them monitoring the level of healthcare they received.

Healthcare professionals, who work with young people who have CF, need to be aware of the needs of young people and their families and respond accordingly. However, this is not a unilateral situation and greater attention needs to be given to addressing these needs by both child and adult services. As the longevity of individuals with CF improves, CF is rapidly becoming a condition that is spanning both child and adult services and within the near future, CF will no longer be considered to be a predominantly childhood condition. It appears however, that service provision has not kept in step with the increase in longevity and despite the recognition of a growing need for adult CF services (West and Mogayzel 2016) little appears to have changed to the present time (Madge et al. 2017).

10.3: Recommendations for Practice

A range of issues were identified by the parents and young people who participated in this study. Based on the results of the study, the recommendations for practice are;

- The information package presented to young people prior to making their transition should include detailed practical information about the adult setting, including telephone numbers, information on clinic attendance, ward facilities and procedures relevant to the management of CF care – for example, the use of an alternative 'overflow' CF ward.
- If there is a delay between completing the transition process in children's services and admission to the adult hospital for any reason, then updated information regarding adult services should be provided at the time of the first admission to the adult CF hospital.
- Staff in child and adult services should work together to support parents in addition to supporting young people during the transition process.

- When young people are placed outside the CF ward, there should be an opportunity for nursing staff on these alternative or overflow wards to receive updated education in the management of individuals with CF
- A hybrid form of FCC / self-care should be used pre and post transition and as part of this *negotiation* between staff, young people and parents should take place to enable parents to continue to have a direct input into their young person's care, if this is required by the young person / parents. This will help prevent a. ineffective 'cliff edge' form of transition provision.

10.4: Recommendations for Further Research

Although this study focused on the experiences of young people (and parents) who made the transition from child to adult services, some other issues of concern were identified. Therefore, based on the results of this study, the recommendations for future research are;

- That a pre and post transition study is undertaken to follow through young people who make their transition from child to adult services. This would enable the recruitment of young people who are closer to the transition point than the participants in this current study.
- That the study be replicated with the intention of capturing participants from a wider geographical area across Wales.

10.5: Limitations of this Study

One of the limitations of this study is that it has been lengthy and it has taken far more time to complete than first anticipated. The main reason for this was the length of time it took to recruit participants. Several recruitment options were used and / or considered and eventually the snowballing method of recruitment was used. One of the methods considered was working with staff at the CF outpatient clinic to recruit staff and as such a meeting was arranged with the CF MDT at the adult CF centre (see section 4.1.3) however, this did not come to fruition. This was unfortunate, as I believe that continued discussion with and participation of the CF MDT could have provided added depth to my knowledge of adult CF care and would certainly have limited some of the challenges I

experienced with recruitment. Working with the CF MDT would have enabled me to access far more potential participants from one centralised point and this could have limited the time it took to recruit participants.

In contrast, I was able to develop a good working relationship with the Public Affairs Officer (PAO) at the CF Trust. She was very helpful and as she had CF herself, she was able to provide an insight into researching with individuals who had CF. Additionally she was prepared to participate in the snowballing process, even after my association with the CF Trust ended. The PAO was a useful connection to have and although I had made contact with her in the very early stages of the study, it may have been beneficial if I had made contact with her before the study had actually started. This would have enabled me to discuss some of the potential pitfalls of recruitment and develop potential strategies for alternative recruitment methods *before* I encountered them. This could have shortened the duration of the recruitment process and negated the need to make several amendments to my ethics applications.

Another limitation of the study was researcher inexperience and my lack of familiarity with IPA. Even though Smith et al. (2009) state that there is no right or wrong way to undertake IPA, there is a process to it and I was anxious to get it right. On first inspection, IPA appears to be process driven and formulaic with a set pattern, which gives the impression is that it is easy to follow. However, with more in-depth reading it became obvious that IPA is more complex and not just a simple step by step process. Consequently, there were times when I struggled with the IPA process and I needed to read and re read around this and although this was not always helpful from a timing perspective, it was necessary to increase my understanding of IPA.

Additionally, with limited interview experience, there were times when, as the transcripts were being reviewed, I realised that some opportunities had been missed with regard to following up a line of questioning. It was also difficult at times to keep the parents on track and this is evident from Sally's interview. At this point, the practitioner took over as I was interested in Sally's experience surrounding her daughter's diagnosis. However, although within IPA participants should be able to discuss what is important to them, my inexperience allowed the participant to wander too far from the point and I failed to keep the interview focused. Consequently, the information regarding transition within Sally's

transcript is limited. It is possible therefore, that with more experience, a greater and more in-depth level of data could have been obtained.

Finally, some of the young people participants were over the original anticipated age group for this study. One participant in particular, (Katie) at the age of 33 years, was much older than the preferred age limit. As a consequence, the length of time since Katie had transitioned was far longer than the other participants and although she appeared to demonstrate a good recall of memory, this could have influenced her responses during the interview.

10.6: Novel Contribution

This research has contributed to the body of literature in that it is the first study to specifically examine the transition experiences of young people with CF and parents in Wales. As such, this has provided a useful insight into the experiences of both the young people and parents with regard to transitioning between child and adult services.

This study demonstrated that young people and parents recognised that transition was necessary and inevitable. However, this study also highlighted that the parents were *not* resistant to transition, but their main concern was that a lack of involvement in their young person's care leading to the inability to monitor their management, could lead to a reduction in healthcare provision in adult services.

It was noted that parents in particular, were open to change prior to transition however, it was their experiences within adult services that heightened their concerns and as such, led them to be concerned about healthcare provision in adult services.

Finally, the unintended consequence of using FCC in the management of young people within children's services is problematic as it has the potential to foster an ineffective 'cliff edge' transition that could have lasting consequences for young people and parents.

10.7: Dissemination of Information

It is proposed that the findings of this study will be written up within a timely manner for publication in a scholarly journal such as the Journal of Adolescent Health, British Journal of Nursing or the Journal of Paediatrics and Child Health.

Every effort will also be made to present the findings at an adolescent health related conference and at the annual CF seminar held in Wales. A copy of the thesis will also be kept in the library of the university where this study was undertaken.

10.8: Personal Comment

It has already been identified (section 9.8) that undertaking this research has enabled me to fulfil an ambition that was first conceptualised in the late 1980s combining my interests in adolescence, CF and transition. However, this would not have been possible without the participants and I am grateful to the young people and parents who participated in this study to fulfil my ambition and expand my knowledge in this area.

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Appendix One

JBI Critical Appraisal Criteria

Sample Critique

Al-Yateem N (2012) Child to Adult: Transitional Care for Young Adults with Cystic Fibrosis. *British Journal of Nursing*, 21 (14) 850-854.

Location of study Republic of Ireland

Criterion	Question(s)	Yes	Some	No
1. Congruity between the stated philosophical perspective and the research methodology	Does the report clearly state the philosophical or theoretical premises on which the study is based? Could have been more clearly articulated		X	
	Does the report clearly state the methodological approach adopted on which the study is based? Phenomenology – but identified as not being ‘pure’ – did not elaborate	X		
	Is there congruence between the two?	X		
2. Congruity between the research methodology and the research question or objectives	2 Is the study methodology appropriate for addressing the research question? Question: to explore the experiences of CF young adults as they transition from paediatric to adult healthcare services	X		
3. Congruity between the research methodology and the methods used to collect data	3 Are the data collection methods appropriate to the methodology? In-depth interviews, which also addresses ethical issues	X		
4. Congruity between the research methodology and the representation and analysis of data	4 Are the data analysed and represented in ways that are congruent with the stated methodological position Followed Van Manen process of coding	X		
5. Congruity between the research methodology and the interpretation of results.	5 Are the results interpreted in ways that are appropriate to the methodology? Two main themes identified, clearly outlined and discussed	X		
6. Locating the researcher culturally or theoretically	Are the beliefs and values, and their potential influence on the study declared? No conflicts of interest declared / written by PhD student / beliefs and values not identified			X
7. Influence of the researcher on the research, and vice-versa, is addressed	Is the potential for the researcher to influence the study and for the potential of the research process itself to influence the researcher and her/his interpretations acknowledged and addressed?			X
	Is the relationship between the researcher and the study participants addressed? Does the researcher critically examine her/his own role and potential influence during data collection? The researcher is not involved in patient care / own role and influence not examined		X	
	Is it reported how the researcher responded to events that arose during the study?			X
8. Representation of participants and their voices	Does the report provide illustrations from the data to show the basis of the conclusions and are participants are represented in the report? Participant quotes clearly identified	X		
9. Ethical approval by an appropriate body	Is there a statement on the ethical approval process followed?			X
10. Relationship of conclusions to analysis, or interpretation of the data	Are the conclusions drawn by the research based on the data collected (data being the text generated through observation, interviews or other processes)? Discussion presented in themes and logical	X		

Appendix Two

Critical Analysis Grid for Personal Referral

Author	Research Question	Participants	Methodology	Findings	Critical comments
AL-Yateem 2012 Rol	What are the experiences of YP as they transition to adult services?	YP / YA Ages not clearly defined N=15	Qualitative In-depth interviews	Need to focus on needs of YP / YA for effective transition	Needed more detail in parts
Anderson et al. 2002 USA + 25 countries	What is the perception of transition programme?	YP/YA (1,288 sent) 334	Quantitative Self administered questionnaires	No significant concerns Nostandard programme Want trans prog	Limited detail re other countries. Not clearly presented
Binks et al. 2007 Canada	What do we know about the transition to adult centred CF care?	Included all articles related to CF and spina bifida 149 Articles reviewed Only 40% research studies	Systematic Review Range of data bases used	Clinicans need to foster autonomy. Need discharge summary. Need to empower YP with knowledge'	CF and spina bifida combined
Boyle et al. 2001 USA	How do parents from paed's view adult prog? What are biggest concerns for parents? What do parents / YP expect from transition?	Young people and parents Pre 52 YP & 38 parents Post 60 patients – average age 29yrs	Quantitative Pre / Post transition face to face survey	Issues not disease specific. Expectations of transition programme Main issue pot. for infection. Parents more concerns re trans than patients	Face to face surveys stated as being anonymous
Brumfield & Lansbury 2004 Australia	What is the exp of Australian YP as they make trans from child to adult care?	YP/YA 19-34 Yrs N=6	Qualitative In-depth interviews	Relationship of YP with Dr/Drs attitude to transition / delivery of age appropriate care all influence YP's experience	Recruitment problems led to snowballing and increasing age limit of participants
Dugueperoux et al. 2008	What are the clinical changes of adults with CF during	Ages not clearly specified	Quantitative Retrospective survey from patients notes	No change in clinical status. Clinicians need greater	Different level of care / facilities for pts with CF in France –

France	transition from paed to adult centre?	Mean age 21yrs N=69		understanding of social / emotional outcomes.	e.g. home physio
Flume et al. 2001 USA	What are the perceptions of paediatric and adult programme directors r/t transition?	Paediatricians and adult physicians N= 104 (total) 72 paed 32 adult physicians	Quantitative Part of larger research study Self administered questionnaires	Considerable differences between paed / adult Drs re concerns of patients, parents & staff	Differences in USA and UK make some findings less applicable
Iles and Lowton 2010 USA	What is the perceived nature of parental care and support for YP prior to transition?	YP 13-24 years & HCPS 50 YP 23 HCPS	Qualitative Face to face interviews	Parents provide financial, emotional and practical support as well as troubleshooting	Need to work in partnership with YP and family Greater understanding of adult CF patients needed.
Madge & Bryon 2002 UK	How effective was the transition model being used?	Young people with CF Aged 14-17 N=21	Audit of service Survey	Transition equated with dying. Stage of growing up.	Unconscious barriers to transition being put up by a range of people
McDonagh et al. 2004 UK	What are the support needs education and training needs of health prof's involved in trans care?	Key HCPs s/workers doctors psychologists youth workers N= 263 22 Involved in trans progs	Quantitative Self administered questionnaire	Education and training needs of HCPs / barriers. Specific area of training needs	HCP's have unmet healthcare needs related to transition
Nasr et al. 1992 USA	Young people's opinions of transition experience	YP/YA Ages not specified N=40	Quantitative Self administered questionnaire	Transition programme made change easier. Adult Dr needed to make time to get to know patient personally	Only 13 participants had actually transitioned

Peter et al. 2009 USA	What is the internists perspective of a transition programme	Physicians 241 stage 1 65 stage 2	Quantitative 2 stage survey - questionnaire	Lack of training for physicians. Parents reluctant to relinquish care.	Lacked clarity in parts
Rutishauser et al. 2014 Switzerland	What are the perceived barriers to transition – what is the preferred age for transition?	Pre 283 Post 89	Quantitative Cross sectional study Self administered questionnaire	Greater attention to transition plan could reduce anxiety and increase trust in HCPs	CF results not clearly presented
Russell et al. 1996 Australia	What are the experiences of adolescents making the transition to adult services?	7 adolescents 8 parents	Pilot study Qualitative Semi-structured interviews	Need for adol. ward M – concerned YP confronted with death	Used Roy Model to Structure
Shaw et al. 2006 UK	What are the transitional needs of adolescents with JIA	Young people Young adults Parents N= 53 YP 12-18 YA 19 -30 Parents Division not clearly specified	Qualitative X 3 Focus Groups	Need developmentally appropriate care based on shared decision making. Issues not disease spec	Transition needs to be adolescent focused

Appendix Three

First Ethical Approval Letter (Young People)

NISCHR

PCU | Permissions
Co-ordinating
Unit

South East Wales Research Ethics Committee
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TA

Telephone : 029 2037 682

South East Wales Research Ethics Committee - Panel D

11 August 2011

Dr Jane Harden
Senior Lecturer
Cardiff University
Level 7 Eastgate House
35-43 Newport Road
Cardiff
CF24 0AB

Dear Dr Harden

Study title: The Transition from Child to Adult Services in Wales:
The Experiences of Young People with Cystic Fibrosis
REC reference: 11/WA/0150
Protocol number: SPON 936-11

Thank you for your letter of 22 July 2011, 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, Dr Craig.

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 study (see "Conditions of the favourable opinion" below).

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer
Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

Fwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board

Appendix Four

Participant Information: Young People

INFORMATION SHEET FOR PARTICIPANTS

Research Study entitled: The Transition from Child to Adult Services: The Experiences of Young People with Cystic Fibrosis in Wales

We (I) would like to invite you to take part in this study but, before you consent, whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information.

1) The purpose of the study

It is well known that the move from child to adult services for young people with an ongoing health care needs can be difficult. It is also recognised that having a transition plan in place can sometimes help with making the move between services. However, little is known about the experiences of young people in Wales when they move from child to adult services. The above study aims to increase the understanding of health professionals about this issue by asking young people with cystic fibrosis (CF) to tell us about their experiences. (This study is being done as part of a Doctoral programme in nursing. Dr Jane Harden is the supervisor for this study).

2) Why have you been chosen?

You have been chosen because you have CF and have already made the transition from child to adult services. You have also shown an interest in taking part in this study by contacting us in response to an advertisement placed on the Cystic Fibrosis Wales Web Page or in the News Letter.

3) Do I have to take part?

No, participation is entirely voluntary. It is important that you read this information sheet carefully and decide whether you would like to take part. If you do decide to take part, you are free to withdraw at any time and without giving a reason. Whether or not you agree to take part in this study, or subsequently withdraw from the study, the care you receive will not be affected at any time.

If you decide to take part in the study, please read and sign the enclosed consent form and return in the stamped addressed envelope provided.

4) What will happen if I decide to take part?

You will be invited to take part in an interview, which will take about 30 minutes and will be tape-recorded. If you agree to be interviewed, the place of interview can be negotiated. For example, you may choose to be interviewed at your home or at another place of your choosing. You are also welcome to have your parent/s, partner or other person who is important to you, sit in on the interview to discuss the study.

5) What are the possible disadvantages and risks of taking part?

There should be no risks or disadvantages in taking part in this study. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

6) What are the possible benefits of taking part?

The information we get from this study, may help young people with CF who make the transition from child and adult services in the future.

7) Will my information be kept confidential?

To assure your privacy and confidentiality, codes instead of names will be used on the tapes. Therefore, any information you provide will be anonymous. We hope to publish the findings from this study but your will not be named, nor will anyone be able to recognise you from the information given, in any publications.

8) What will happen to the results of the research study?

We hope to publish the findings from this study in nursing journals, and to present the findings at national and international conferences.

9) Who has reviewed the study?

This study has been reviewed by expert nurse researchers, the Trusts' Peer Review Committees, the University Peer Review Committee and the Local Research Ethics Committee.

We would be pleased if you feel that you can give up some time to take part in this study.

Contact for further information

If you require any further information, please contact Siân (or Jane) on the numbers or email addresses below.

Mrs Siân Bill

Tel: 02920 917754

Email: bills@cardiff.ac.uk

Dr Jane Harden (Supervisor)

Tel: 02920 917725

Email: hardenj@cardiff.ac.uk

Appendix Five

Consent Form Young People

CONSENT FORM

Title of Study: **The Transition from Child to Adult Services: The Experiences of Young People with Cystic Fibrosis in Wales**

Name of Researchers: Mrs Siân Bill (Dr Jane Harden)

Please initial box

1. I confirm that I have read and understand the information sheet for the above study dated August 2013 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and I have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

Appendix Six

Message for CF Trust Web Page

Hello,

I would like to introduce myself. My name is Siân Bill and I am a lecturer in nursing at Cardiff University. I have been interested in CF for a long time and over the years this has been a main focus of my clinical practice (including some time as a CF consultant nurse in Australia). I also have a special a special interest in young people's health.

At the moment I am a student at Cardiff University studying for a doctorate. As part of this I need to do some research. My research is related to young people's experiences of moving from child to adult services in Wales. So, I am looking for young people who are interested in taking part in this study. It will mean being interviewed, when you will have the opportunity to talk about your experience. The time and location of the interview can be negotiated.

If you are interested in finding out more about the study, or if you would like to take part, my contact details are as follows

Email: bills1@cardiff.ac.uk , Landline (office hrs): 02920917754, Mobile: 07841585625 (text or phone).

I would really value your input, so I would be grateful if you would give this some consideration.

Thank you for your time

Siân

Appendix Seven

Second Ethics Approval Letter (Parents)

NISCHR

wasanaeth
Moeseg
Ymchwil

RES

Research
Ethics
Service

Wales Research Ethics Committee
Sixth Floor, Churchill
17 Churchill
Cardiff CF10 1TL

Telephone: 029 20 75 55 55

E-mail: jagjit.sidhu@wales.nischr.ac.uk

Website: www.hra.nischr.ac.uk

02 October 2014

Dr Jane Harden
Senior Lecturer
Cardiff University
Eastgate House
5-43 Newport Road
Cardiff
CF10 0AB

Dear Dr Harden

Study title: The Transition from Child to Adult Services in Wales
EC reference: 11/WA/0150
Protocol number: SPON 936-11
Amendment number: Amendment 3
Amendment date: 18 August 2014
IS project ID: 71279

The above amendment was reviewed at the meeting of the Sub-Committee held on 02 October 2014.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion on the basis described in the notice of amendment form and supporting documents.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	Amendment 3	18 August 2014
Participant consent form	1	01 September 2014
Participant information sheet (PIS)	1	01 September 2014
Research protocol or project proposal	3	01 September 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Appendix Eight

Participant Information Parents

INFORMATION SHEET FOR PARTICIPANTS

Research Study entitled: The Transition from Child to Adult Services: The Experiences of Young People with Cystic Fibrosis and their Parents

We (I) would like to invite you to take part in this study but, before you consent, whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is not clear or if you would like more information.

1) The purpose of the study

It is well known that the move from child to adult services for young people with an ongoing health care needs can be difficult. It is also recognised that having a transition plan in place can sometimes help with making the move between services. However, little is known about the experiences of young people and their parents in Wales when they move from child to adult services. The above study aims to increase the understanding of health professionals about this issue by asking young people with cystic fibrosis (CF) and their parents to tell us about their experiences. (This study is being done as part of a Doctoral programme in nursing. Dr Jane Harden is the supervisor for this study).

2) Why have you been chosen?

You have been chosen because you have a son or a daughter who has CF and has already made the transition from child to adult services. You have also shown an interest in taking part in this study by contacting us in response to a request from other young people who have CF and their families.

3) Do I have to take part?

No, participation is entirely voluntary. It is important that you read this information sheet carefully and decide whether you would like to take part. If you do decide to take part, you are free to withdraw at any time and without giving a reason. Whether or not you agree to take part in this study, or subsequently withdraw from the study, the care your son or daughter receives will not be affected at any time.

If you decide to take part in the study, please read and sign the enclosed consent form and return in the stamped addressed envelope provided.

4) What will happen if I decide to take part?

You will be invited to take part in an interview, which will take about 30 minutes and will be tape-recorded. If you agree to be interviewed, the place of interview can be negotiated. For example, you may choose to be interviewed at your home or at another place of your choosing. You are also welcome to have your partner or other person who is important to you, sit in on the interview to discuss the study.

5) What are the possible disadvantages and risks of taking part?

There should be no risks or disadvantages in taking part in this study. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

6) What are the possible benefits of taking part?

The information we get from this study, may help young people with CF and their families who make the transition from child and adult services in the future.

7) Will my information be kept confidential?

To assure your privacy and confidentiality, codes instead of names will be used on the tapes. Therefore, any information you provide will be anonymous. We hope to publish the findings from this study but your will not be named, nor will anyone be able to recognise you from the information given, in any publications.

8) What will happen to the results of the research study?

We hope to publish the findings from this study in nursing journals, and to present the findings at national and international conferences.

9) Who has reviewed the study?

This study has been reviewed by expert nurse researchers, the Trusts' Peer Review Committees, the University Peer Review Committee and the Local Research Ethics Committee.

We would be pleased if you feel that you can give up some time to take part in this study.

Contact for further information

If you require any further information, please contact Siân (or Jane) on the numbers or email addresses below.

Mrs Siân Bill

Tel: 02920 917754

Email: bills@cardiff.ac.uk

Dr Jane Harden

Tel: 02920 917725

Email: hardenj@cardiff.ac.uk

Appendix Nine

Consent Form for Parents

CONSENT FORM

Title of Study: **The Transition from Child to Adult Services: The Experiences of Young People with Cystic Fibrosis and their Parents**

Name of Researchers: Mrs Siân Bill (Dr Jane Harden)

Please initial box

1. I confirm that I have read and understand the information sheet for the above study dated September 2014 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and I have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

☐

3. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

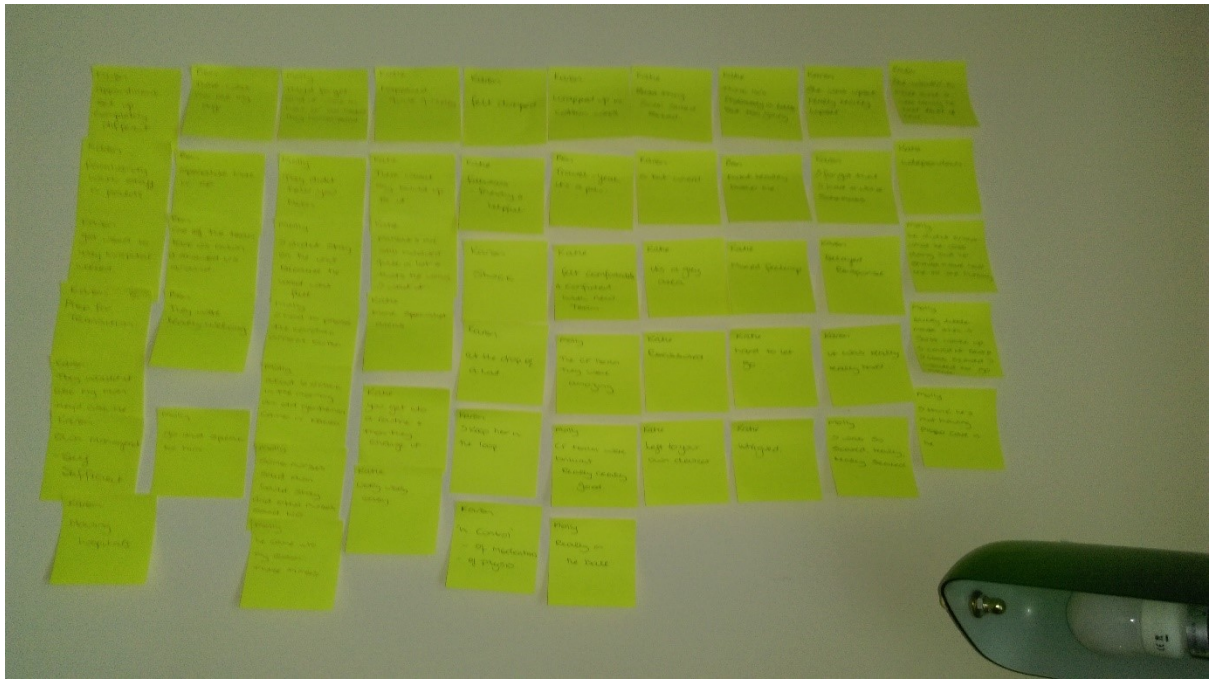
Name of person taking consent

Date

Signature

Appendix Ten

Photograph of IPA Post it Notes



Appendix Eleven

Mind Map: Young People

Caron
Prop needs
growth/development
sense of loss
being in care
being a control
Expect patient
Staff relationships

Ben
Not a Big deal
Travel
Freedom
More up than
Step - or
Staff specialist

Preparation

Staff Related

Impact on
YP

Expect
patient

ly
p needs
environment
act on yp
going to school
act on family
attitudes
couldn't stay
lost next location

Katie
Prop / process
parental involvement
Staff issues
not sorted out
Reassured about
Expect PT
moved close

Environment

Impact on
family

Appendix Twelve

Mind Map: Parents

PREP

1) Jenny
 (Pre prep)
 Lack of family
 Knowing what goes on
 Sense of loss
 Care issues
 Ongoing support
 Impact on family
 Expert panel

2) Sally
 Limited the team
 Person seen
 diagnosis
 politicised
 Environment of care
 Staff issues
 preferred to prep needs
 Expert panel

3) Jeff
 Sense of loss
 loss of control
 - Best person to provide care.
 pre was prep
 not able to stay
 Difficulty letting go
 Environment of care
 politicised
 Expert panel

Staff
 Care
 Pre was info
 Sense of loss
 Environment of care
 Safety issues
 Critical Incident
 Organisation of staff
 Cross infection
 No trying to change
 Expert panel
 Staffing

LOSS
 Environment of care

Care
 Pre was info
 Sense of loss
 Environment of care
 Safety issues
 Critical Incident
 Organisation of staff
 Cross infection
 No trying to change
 Expert panel
 Staffing

Expert panel
 Impact on family

Staffing
 Damage