

The transition to adulthood for young people with Cystic Fibrosis

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Declaration

I declare that:

No portion of the work referred to in this thesis has been submitted in support of an application for another qualification of this, or any other University or Institute of learning.

Joanne Hogan.

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Abstract

The aim of this qualitative grounded theory study was to provide insight into the subjective worlds of young people with CF currently undergoing the transition to adulthood. The preliminary stage of the research was to post a message on the Cystic Fibrosis (CF) Trust internet forum for young people with CF. The message gave details of the study and asked the young people to identify areas they felt worthy of study in relation to the transition to adulthood. Responses were used to devise initial interview topics for the second stage of the study.

Once ethical approval had been obtained a purposive sample of young people with CF was recruited through two local regional hospitals. A total of eighteen participants were recruited and interviewed, ten females and eight males, all between the ages of 16-21 years. Initially interviews were unstructured and aimed at getting participants to open up and identify what was important to them. As data collection progressed the interviews became more focused and hence semi-structured.

Interviews were coded and analysed using the grounded theory methodology.

Analysis generated a core category and six other salient categories. The core category centred on the concept of normality. Being normal and leading a normal life was of primary importance to all of the young people but the notion of normality held very different meanings and connotations. The way in which they conceptualised normality within the context of their own lives had far reaching consequences and impacted upon many areas of their lives including: how they constructed their identities; their goals and aspirations for adult life; decisions of disclosure; their

attitudes towards treatment; how they coped with CF and their willingness to accept support from others. Findings of the present study have highlighted a number of implications for both practice and future research.

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CHAPTER 1

INTRODUCTION AND OVERVIEW OF THE THESIS

1.1 Introduction

Transition to adulthood is a major milestone only recently actualised for young people with Cystic Fibrosis (CF). In recent years much progress has been made in the identification and early treatment of CF and subsequently there has been a dramatic increase in life expectancy (Carpenter & Narsavage, 2004). These advances have opened up the possibility for many young people with CF to achieve the major milestones of adulthood (Badlan, 2006).

There is a consensus within the literature that having a chronic illness adds a further dimension to adolescence and presents additional and unique challenges in the transition to adulthood. However, much of this literature is descriptive in nature and lacks insight into how the dynamics of transition to adulthood operate for those with CF (Riddell, 1998). Very little research has addressed the transition to adulthood for those with a chronic illness; even less has focused specifically on young people with CF, and currently very little is known about this stage of their lives.

The overall aim of the present study was to provide insight into the subjective worlds of young people with CF currently undergoing the transition to adulthood. Such research is needed to enable the delivery of services that are sensitive to the needs and priorities of young people with CF.

1.2 Overview of thesis

Chapter 2: This chapter provides a brief introduction to CF before moving on to review the literature on chronic illness and disability from a number of different perspectives pertinent to the present study, these are: sociological approaches, disability studies and psychological approaches. It is acknowledged that adolescents with CF will have to deal with general issues of the transition to adulthood as well as issues relating to their condition. Therefore, this chapter provides a brief outline of the literature on adolescence and the transition to adulthood before turning to the literature that addresses this stage of life specifically for chronically ill and disabled young people. This chapter then considers research that has specifically examined the views and experiences of chronically ill and disabled young people. Finally, a summary of the chapter and rationale for the present study is presented.

Chapter 3: This chapter provides an overview of the methodological approach adopted for the present study. It first presents the philosophical background of the present study and explains why the grounded theory methodology was chosen. Following on from this the chapter then

provides a review of the grounded theory methodology including its background, strategies, data collection methods, ethical implications and finally how rigour can be ensured in a grounded theory study.

Chapter 4: This chapter outlines the methods used at each stage of the present study. It first outlines the preliminary stage of the study and provides a brief summary of the results from this stage. The chapter then moves on to provide an overview of the interview stage of the study and the methods used and in doing so it addresses the following: sample selection; recruitment procedures; the interview process; providing participant feedback; obtaining participants medical information; analysis of data and finally, ethical considerations.

Chapter 5: This chapter first provides an overview of the ways in which data from the present study were analysed. A short summary of the seven salient categories identified through analysis follows before an outline of the development of the core category. The chapter then discusses the presentation of results for a grounded theory study and specifies how the results of the present study will be presented. Finally, the findings of the study are presented according to the core category and the three identified subgroups.

Chapter 6: This chapter first provides a discussion of the findings from the present study within each of the seven salient categories identified. Findings for each of the categories are linked back to the relevant literature as reviewed in Chapter 2. The chapter then returns to the rationale for and initial objectives of the present study as outlined in chapter 2 to address how the findings

of the present study can add to and expand upon current knowledge and thinking in this substantive area. The limitations of the present study are then identified and finally the implications of these findings for both practice and future research are discussed.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction to Cystic Fibrosis

Cystic Fibrosis (CF) is the UK's most common life threatening inherited disease, affecting over 8000 people. The condition is usually recognised in infancy or early childhood and each week in the UK five babies are born with CF (CF Trust, 2007). The disease is caused by mutation of a single gene but there are over 600 different mutations and the severity of symptoms varies not only between individuals but also over the course of the lifespan (Small & Rhodes, 2000).

CF is a complex disease which may affect various body organs, but the two main areas affected are the lungs and the pancreas. It causes glands in the body to produce abnormally thick and sticky mucus secretions, which block or clog the bronchial airways and the digestive system (CF Trust, 2007). If left untreated the mucus in the airways of the lungs builds up and becomes the site of recurrent bacterial infections which leads to progressive damage and ultimately respiratory failure. The mucus also obstructs the pancreas and blocks the passage of digestive enzymes to the small intestine which untreated leads to malabsorption, vitamin deficiency, weight loss and ultimately severe malnutrition (Small & Rhodes, 2000; Pownceby, 1995).

There is currently no cure available for CF and it remains a progressive and ultimately fatal disease. However, in recent years much progress has been made in identification and early treatment of CF, thus resulting in longer life expectancy (Carpenter & Narsavage, 2004). Fifty years ago children with CF almost inevitably died in early childhood but median life expectancy has now reached 31 years (Esmond, 2000; CF Trust, 2007). For those born in the 1990's it is estimated that over 90% will reach adulthood and median life expectancy is expected to reach around 40 years (Elborn, Shale & Britton, 1991). Increasing survival rates have therefore changed the boundaries of CF from an exclusively childhood chronic illness to one that affects both children and adults (Esmond, 2000).

Many people with CF are now surviving into adulthood and living well into middle age. This has brought with it the need for people with CF and professionals who provide medical and psychosocial services to develop ways to deal with the disease during adulthood (Palmer & Boisen, 2002) and indeed during the transitional phase between childhood and adulthood.

People with CF are now usually able to keep themselves in reasonably good physical condition, which gives them the opportunity to lead a relatively normal life. However, there is a catch as this can only be achieved by adhering to a strict, complex and time consuming therapeutic schedule, thereby introducing an abnormal element into a normal life (Havenmans & Bocck, 2007). People with CF are expected to incorporate a variety of treatments into their daily lives in an attempt to delay the progression of the disease. Most undergo twice daily sessions of chest physiotherapy which helps to expectorate the mucus from the lungs. These sessions can be

difficult to carry out without assistance. Antibiotics are taken orally or inhaled to both prevent and treat infections. In cases of acute infection antibiotics are delivered intravenously. Pancreatic enzymes must be taken before each meal and many people also take vitamin supplements to counter the problems of malabsorption. A high calorie diet is also essential to ensure adequate nutrition (Small & Rhodes, 2000; Pownceby, 1995). These treatments need to be performed on a daily basis regardless of current clinical status and symptoms.

As the disease progresses the frequency of hospital visits and complexity and intensity of the treatment regime is likely to increase. Nocturnal nasogastric or gastrostomy feeds may be introduced to maintain body weight and aggressive antibiotic treatments and the use of oxygen will become increasingly necessary as breathing becomes more difficult. In addition as people are living longer with CF the risk of further complications increases such as: CF related diabetes; bone disease; liver disease and fertility problems all of which may further add to the complexity of treatment regimes (CF Trust, 2007).

Research focusing on children and adults living with CF and chronic illness/disability more broadly has used a number of different perspectives and the most common ones pertinent to the present study are reviewed below. These are sociological approaches, disability studies and psychological approaches.

2.2 Sociological approaches to chronic illness and disability

The first sociological perspective to develop a distinct analysis of health and illness was functionalism. In his explanation of social systems, Parsons (1951) defined health as a normal and stable state whilst illness was seen as a form of social deviance. Parsons (1951) was concerned with the importance of health to the functioning of the social system as a whole. He defined illness as a social role – the sick role. The sick role allows the sick person to be exempt from normal social roles but in return the sick person is obliged to do everything possible to achieve the goal of complete recovery. This implies that the sick role cannot be applied to chronic illnesses (Young, 2004). Parsons' approach has received considerable criticism for its simplistic view of social consensus and for characterising illness by dependency, regression and, through encounters with qualified practitioners, hopefully recovery (Bury, 1991).

Armstrong (1994) stated that Parsons' work is associated with a consensus model of the doctor-patient relationship, which characterises a passive and obedient patient. In the 1970's sociologists began to challenge the notion that a consensus between doctor and patient was inevitable and this led them to propose a conflict model. He also noted that more recently, sociologists have proposed a negotiation model which stresses the active role that patients play. People with chronic illness now expect to be empowered to participate in decision-making. However, in a study of adults with diabetes, participants identified two ways in which practitioners contradicted this: by discounting the experiential knowledge of patients and by failing to provide the resources necessary for patients to make informed decisions (Paterson,

2001'). Paterson concluded that some practitioners still act according to the traditional bio-medical model where professionals are the ultimate decision makers.

Young (2004) noted that labelling theory as proposed by Becker (1973) represents an alternate model to the sick role. In illness the physician labels the patient with a diagnosis and prognosis of the illness based on the social, cultural and biological mores of the physician's view of illness. The patient may accept or reject this label but either way it has consequences for them. Labelling theory can be criticised in its application to illness due to a lack of a comprehensive explanatory viewpoint.

A potential consequence of being labelled with an illness is stigmatisation. The concept of stigma was brought into sociology by Goffman (1963). Stigmatisation is the process in which social meaning is attached to behaviours or individuals and occurs when evidence exists of an attribute that makes an individual different and less desirable for example, physical deformity. Goffman argued that stigma can be understood as the discrepancy between an individual's desired and actual social identity; this discrepancy results in a spoiled identity (Goffman, 1963). Goffman distinguished between two classifications of stigma: discredited and discreditable. A discredited condition is where visible signs of difference can be seen. A discreditable condition is one that is invisible and hence not yet discredited. This creates the problem of whether to disclose the condition or attempt to 'pass for normal'. Goffman has been criticised for depicting people who are stigmatised as relatively passive recipients of a spoiled identity. There is now a growing body of normalisation literature that documents the complex and creative strategies

people use to cope with their condition and feel part of society (Joachim & Acorn, 2000¹). In spite of such criticism the stigma framework has remained predominant in illness studies (Bell, 2000).

In Britain, research on the sociological dimensions of chronic illness began in the 1960's.

Functionalism was largely overtaken by writers adopting a broadly interactionist and interpretative approach to the experience of illness (Barnes, Mercer & Shakespeare, 1999).

Sociological research began to document the ways chronic illness influences daily living, social relationships and a person's sense of self and identity (Barnes & Mercer, 1996). Bury (1996) identified two seminal works in the field of chronic illness and disability. In Britain Blaxter's (1976) research revealed the impact of disability on people's lives over time, noting problems that participants and their families faced. In the US Strauss and Glaser (1975) published their work on chronic illness and quality of life. They identified the balance people with chronic illness sought to strike between the demands of the illness and treatment regime and the need to maintain a normal everyday life.

The World Health Organisation's, International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980) provided a focus for subsequent sociological research on chronic illness and disability. Bury (2000) noted that this scheme suggests a sequence of events based on an initial causal mechanism of disease or active pathology. Thus, health status is seen as a central element in the disablement process. Previously within the field of chronic illness the documentation of the problems faced by patients tended to dominate the research. However,

since the 1980's research findings have also been documenting the positive steps people take to manage, mitigate or adapt to chronic illness and the meanings attached to these actions. This is reflective of a change in emphasis to a more theoretically informed approach to chronic illness, that is interpretive sociology which views people as active agents. Bury (1997) identified three aspects of the experience of and response to chronic illness within this work:

- **Biographical disruption** – the onset of illness exposes the individual to a threat to their self-identity and a potentially damaging loss of control (Bury, 1988). From her work on how people with chronic illness experience a loss of self, Charmaz (1983; 1991) postulated that following the onset of chronic illness people often experience a deteriorating self image, live restricted lives, are devalued as less than normal and feel they are a burden to others. This reduces their self worth until some alternative means of satisfaction can be found.
- **The impact of treatment on everyday life.**
- **Long-term adaptation to and management of illness and disability**, which is undertaken as people try to reconstruct a normal life. Bury (1991) believed it was necessary to distinguish between coping, strategy and style. Coping refers to the cognitive processes whereby the individual learns how to tolerate the effects of illness and maintain a sense of self worth in the face of disruption. An example of coping would be normalisation. The term strategy refers to the actions people take in the face of illness to mobilise resources and maximise favorable outcomes. Style refers to the way people respond to and present important features of their illnesses or treatment regimes.

In their study of adults with CF Lowton and Gabe (2004) used Bury's definitions to identify three distinct modes of coping: making comparisons to others; maintaining a positive attitude and acknowledging a loss of spontaneity. They also identified two styles used by participants; fraudulence and denial. Fraudulence was a style used by the adults to maintain the perception of their health as 'normal' as they felt that they were a fraud in their claim to be a person with CF.

The study of chronic illness has been an important way of examining aspects of identity, social interaction, experience of stigma and the body in late modern society (Bury, 1997). However, much of this work has focused on those who have acquired a chronic illness after a long span of good health rather than those born with a chronic illness such as CF. There remains much interest in the impact of chronic illness on a person's identity and sense of self within sociological work.

The public and shared aspects of a person's identity establish what and where that person is within social structure and identity defines a person as a social object located into group membership and social relationships (Kelly & Field, 1996). Core identities consist of a person's gender, age and ethnicity whilst other identities reflect personal qualities or primary role activities that can be impacted upon by chronic illness (Kelly and Field, 1996). However, Kelly and Field (1998) stressed that chronic illness may not be disruptive for everyone, as people have any number of bases available for identity construction. In addition chronic illness may become a stable orienting aspect of an individual's life providing shape, meaning and coherence to them.

Joachim and Acorn (2000¹) noted that researchers have traditionally studied and interpreted the chronic illness experience through a lens of either normalisation or stigma. However, they argued that in order to capture and understand the experience of people with chronic conditions, researchers should consider the interdependence of the two perspectives and avoid assumptions that derive from stigma or normalisation alone. They argued that consideration of both perspectives would facilitate a broader and more accurate understanding, as failure to look through both lenses would ensure that half the picture is missing.

Researchers who study chronic illness through a normalisation lens have described the process as one of actively adapting to changes wrought by the condition (Joachim & Acorn, 2001¹). Some researchers have described normalisation as a process in which, the person with a chronic illness chooses to function effectively and be perceived as normal (Deatrick, Knafl & Murphy-Moore, 1999). Other researchers have described normalisation as a common management strategy among persons with chronic conditions (e.g. Darling & Darling, 1982). In contrast some researchers describe the process of normalisation for those with a chronic illness as perceiving and describing their lives as normal even in the face of numerous difficulties (e.g. Miller, 2000).

Strauss, Corbin & Fagerhaugh *et al.* (1984) described normalisation as a basic strategy used by the chronically ill to establish or maintain a normal life despite the disease and its symptoms. Their view assumed that ill people themselves take part in the normalisation process. They argued that normalisation tactics will vary along the illness trajectory. Chronically ill people will move from acting as anybody else to acting normal under special circumstances as the disease

progresses. This will require a redefinition of normality. Researchers who have considered the role of social support in the normalisation process have found that it helps those with a chronic illness develop a more positive sense of self (e.g. Charmaz, 1983).

Thorne (1993) conducted a qualitative exploration of the chronic illness experience from the perspective of chronically ill patients and their families. She found that the idea of normal held much meaning for patients and their families and they often cited normal as a reference point from which to describe their own unique experiences. For some normal meant being able to fit in and was seen as a social abstraction and an ideal. For many the experience of chronic illness had altered their sense of what was normal and through normalisation the work of managing their chronic illness became a normal part of daily life. Such normalisation presented a number of advantages. For many patients redefining themselves in terms of a modified notion of normalcy had helped them to create a positive attitude towards living with chronic illness. Finding ways to feel normal was an important strategy to minimise some of the social effects of having a chronic illness and to minimise the significance of limitations.

However, a number of participants articulated a perspective that depicted sharply from such normalising. From their perspective such a strategy could create serious problems and lead to a denial of the implications of their illness. At some point in their chronic illness experience these participants had come to realise that normal was largely an artificial construct that they had blindly accepted as valid. Many of them were surprised by the extent to which assumptions of normality had shaped their early adjustment to chronic illness. Rejecting the social value of

normalcy had, they felt, freed them to adopt unique and individualised solutions to the problems they faced.

The accounts generated through this study portrayed that normal is a highly charged concept that has considerable impact in shaping the way chronically ill people define themselves, manage their lives and cope with the abnormalities of illness (Thorne, 1993). Thorne concluded that normalisation can be a double edged sword with beneficial consequences under some circumstances and crippling ones under others. She further noted that the advantages of normalisation have attained widespread acceptance within the health care community. However, it should be recognised that such a strategy can disadvantage some individuals for whom it represents a subtle but penetrating form of denial.

Joachim and Acorn (2000¹) stated that in general when the literature on chronic illness is considered through a normalisation lens the experience is best understood in terms of the strategies people use to cope, feel part of society and counter the effects of stigma. The normalisation process values control over symptoms and the ability to make life as normal as possible. However, this perspective may underestimate the power of social context and the impact it can have (Joachim & Acorn, 2000¹).

In spite of the growing body of normalisation literature, Goffman's (1963) work on stigma has also remained influential in the sociological study of chronic illness. In recent years the concept

of stigma has attracted increasing attention among health professionals as it is thought that stigma may contribute to the burden of illness and influence the effectiveness of treatment (Weiss, Ramakrishna & Somma, 2006). Joachim and Acorn (2000¹) stressed that the conclusion of research using a stigma lens is usually that stigma is not under the control of the individual. Therefore, the individual with a chronic illness is portrayed as a victim of prevailing norms. They noted how research through a stigma lens tends to highlight the relationship between society and the person with a chronic illness. Such research provides an overview of how society treats a person with a chronic illness and focuses on the negative and challenging social context within which a chronic illness is lived (Joachim & Acorn, 2000¹). They argued that researchers using a stigma lens only, overlook the momentum and energy in the normalisation process.

Coping with stigma involves various strategies including decisions about disclosure for those with invisible illnesses (Joachim & Acorn, 2000²). Difficulty in disclosing is related to the belief that the response of others will be negative and disclosure runs the risk of rejection and loss of control (Charmaz, 1991). Joachim and Acorn (2000²) argued that the management of information in the lives of people with chronic illness is critical. They identified two ways in which people with invisible illnesses may disclose: spontaneously or in a protective manner where they control how, what, when and who is told about the condition. They noted that currently little is known about people's decisions regarding disclosure and how they cope with the results of their decisions. They stressed that understanding of how individuals experience chronic conditions in terms of visibility has implications for both research and practice.

In relation to disclosure, Lowton (2004) conducted interviews with adults with CF aged 18-40 years. She identified three situations of disclosure: low-risk situations; medium-risk situations and high-risk situations. In all situations disclosure was seen as a risk due to the potential consequences, both positive and negative. In all situations, state of health, the body and its changes with increasing illness were significant factors in the decision to disclose or conceal the condition.

Low-risk situations were casual encounters with a low level of intimacy in which, participant's felt that there was a slim chance of discovery if they chose to conceal their CF. In these situations identity as a normal adult was usually assured and felt or enacted stigma was not an overriding factor due to the perceived ignorance of the general public about CF. Rather than the fear of stigma it was the level of "botherment" that participants' perceived they would experience in having to explain the condition to others who had little knowledge of it.

Friendships were classed as medium-risk situations and here the perceived reaction of others began to influence decisions about disclosure. In these situations the risks and benefits of disclosure were considered more carefully. Participants used past experiences of disclosure to inform their decisions of when to disclose to friends. Perceived level of intimacy with friends was a significant factor and decisions were often based on the quality of a relationship.

Participants expressed a fear of being treated differently, as a patient rather than a friend.

Disclosure to a potential partner or prospective employer was classed as a high-risk situation as there is a much greater chance of discovery. In these situations disclosure was perceived to hold great difficulty due to the significance of possible consequences. In decisions about disclosure to a potential partner, level of intimacy and perceived reaction were again significant factors. Early on in relationships partial disclosure was common. A major issue identified by participants was fertility and the risk of rejection by a potential partner due to infertility.

2.2.1 Criticisms of sociological approaches

There have been a number of criticisms of sociological approaches to chronic illness and disability. The socio-medical model of chronic illness and disability adopted by sociologists has come under heavy criticism from disability theorists for its causal link between impairment and disability. As discussed below, proponents of a social model of disability have argued that disability is a problem entirely social in nature. In response to this Bury (2000) noted that the ICIDH (WHO, 1980), definition, which underpins the socio-medical model, does recognise that disability is influenced by context and culture however, he also argued that some of the key features of disability are clearly the result of illness and impairment. He believed that the socio-medical model occupies a meeting point between the direct effects of chronic illness and impairment and the social context in which people live.

Whilst there is a preoccupation with the meanings of illness in sociological work, Bury (2000) stressed this extends from cognitive to cultural and structural issues. He highlighted his previous

work, which identified at least two core senses in which meaning is used in the context of studying chronic illness (Bury, 1988). The meaning of illness in terms of its consequences refers to the material and practical difficulties that flow from emerging disability and the surrounding environment. The meaning of illness in terms of its significance refers to the way alterations in the body interact with wider social, cultural and structural contexts. This goes beyond practical consequences to issues of appearance, social performance and thus identity.

Whilst sociological research and writing on chronic illness is now extensive, most of this work either focuses on the experiences of adults or takes an adult centered view of the experiences of children and young people. In addition the specific ways in which age shapes the experience of chronic illness has typically been ignored by researchers and rarely are distinctions in illness experience conceptually linked to issues of living at a particular developmental stage (Thorne & Paterson, 2000).

Bury and Gabe (2004) noted that there are few sociological accounts of chronic illness that do not acknowledge that basic to the experience of illness is disruption to a normal and usually desired routine of everyday life. However, the majority of accounts have centered on adults who have generally enjoyed a long span of good health before suffering the onset of symptoms (Lowton & Gabe, 2004). Whilst some attention has been given to chronic illnesses diagnosed in childhood the focus has firmly been on the child and their family.

Much of the sociological work cited above has been carried out by able-bodied people and those without a chronic illness. In contrast, there is a body of work led by disabled people which places great emphasis on the role of society in disabling people and the negative consequences this can have for individuals. This perspective is reviewed next.

2.3 Disability Studies

For most of the twentieth century in Western societies, disability has been equated with flawed minds and bodies. The individual's impairment necessitates dependence on family, friends and welfare services and disability amounts to a 'personal tragedy' and a social problem or burden for the rest of society. However, since the late 1960's this orthodoxy in both thinking and practice has become the target of campaigns across Europe and North America (Barnes & Mercer, 2003). Disabled people took the lead in campaigning and by the early 1970's two organisations had been formed in Britain: the Disablement Income Group and the Union of the Physically Impaired Against Segregation (UPIAS). These organisations raised the concerns of disabled people onto the political agenda (Oliver, 1996).

The UPIAS (1976) produced a manifesto entitled Fundamental Principles of Disability, which, asserted that it is society that disables people with impairments. It defined disability as something imposed on top of impairments by society and therefore defined disabled people as an oppressed group within society. The UPIAS analysis of a disabling society is built upon a clear distinction of impairment and disability. Impairment is defined as "Lacking part or all of a limb,

or having a defective limb, organ or mechanism of the body.” Disability is defined as “The disadvantage of restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.” (UPIAS, 1976, p. 3-4).

This distinction enabled the development of a social model of disability, which rejects an individualistic approach to disability and locates disability squarely within society (Oliver, 1996). The social model of disability has challenged the personal tragedy view of disability that informs medicine, rehabilitation and broader cultural thinking about disability (Thomas, 1999). It is recognised that the social model is only a stepping-stone to building a social theory of disability. However, it quickly became the basis for disability awareness (Oliver, 1996).

In recent years disabled people both individually and collectively have rejected the personal tragedy approach to disability instead adopting the principles of the social model. A vast amount of literature both on and more recently with and by disabled people has contributed to this approach, which is now broadly termed ‘disability studies’. Barnes & Mercer (1996) noted that the focus for much of this is the social and economic disadvantage and discrimination experienced by disabled people. Within disability studies there has also been much critique of the established definitions and language used in relation to disability. One consequence of this is that within disability studies the phrase ‘disabled people’ is used, as opposed to ‘people with disabilities.’ Barnes and Mercer (2003) advocated the use of the term ‘disabled people’ as it emphasises the ways in which social barriers affect life chances.

Disability theorists have been particularly concerned with the way in which disabled people are socially oppressed as a result of social and environmental barriers such as lack of equal access to employment, transport, housing and services as well as discrimination and prejudice. Marks (1999) stated that disabled people remain one of the poorest and most oppressed sectors of society in the UK and USA. The effects of their unequal opportunities in employment are seen not only in terms of the actual numbers employed but also in levels of pay and type of occupation (Arthur & Zarb, 1995).

A further concern has been the role of medicine and health professionals in the lives of disabled people. Oliver (1996) argued that the medicine and rehabilitation enterprise is founded upon the ideology of normality and restoring the person to a normal state. Medicine is seen to contain a series of latent normative assumptions about value, beauty and function (Marks, 1999), all of which serve to devalue those with impairments. Professionals involved in the lives of disabled people often hold much power over the individual and act as gatekeepers to a wide range of resources (Marks, 1999). Davis (2004) stressed that this is a particular concern for disabled children and young people, as professionals may assume they are unable to put forward their own solutions and therefore disregard their feelings and opinions on matters of concern.

Disability theorists have drawn attention to culture, media and representation as playing an important role in the oppression of disabled people. It is felt that the socially dominant culture shapes the way in which they are viewed and this has contributed to the oppression of disabled people (Riddell & Watson, 2003). Morris (1991) noted that they are typically missing from

mainstream culture. Language is often used to separate them from society through labelling. Words used to describe disabled people are almost invariably negative or passive and they are described as sufferers or victims who are thought to have needs rather than rights (Swain, French & Cameron, 2003). Swain *et al.* argued that impairment represents a threat to the established notion of normality and they noted that the majority of disabled people are well into adulthood before they manage to abandon or at least challenge these expectations of normality.

The misrepresentation of disabled people by charitable institutions is a particular concern for disability theorists as many people learn about disability through the media (Barnes, 1992). Charities often portray disabled people as socially isolated passive recipients of caring attention (Wales, 2004), as they seek to generate pity and sympathy in an attempt to motivate the general public to donate money (Shakespeare & Watson, 1998).

There is an interest within disability studies of the role of culture in shaping the identity disabled people take on for themselves (Swain *et al.*, 2003). In recent years the question of identity has become central within disability studies (Scott-Hill, 2004), in particular the rapidly growing body of affirmation literature (Darling, 2003). An affirmation model of disability rejects the tragic view of disability and encompasses positive social identities both individually and collectively for disabled people (Swain & French, 2000). This involves the disabled individual asserting a positive identity in being disabled and actively rejecting the dominant value of normality. This occurs through a process of coming out, where the individual redefines their personal identity, no longer regarding disability as something to be hidden but rather as an imposed social category to

be challenged. Identifying as disabled goes against the stream and is a declaration of belonging to a devalued group within society. Swain *et al.*, (2003) argued that this identification offers disabled people a positive self-regard and represents a move from the personal tragedy view to the social model view of disability.

However, Darling (2003) noted that not all disabled people share a common perspective. She argued that the actual identity of disabled people remains an empirical question and that we need to understand all segments of the disabled population. A number of variables may affect identity including the nature and visibility of impairment. Shakespeare & Watson (2002) stated that some people with hidden impairments may be less likely to come out as disabled and move to a positive acceptance of difference, instead choosing to maintain a normal identity by passing as non-disabled. This refusal is sometimes seen as internalised oppression which, they argued is both patronising and oppressive in itself as people have choices as to how they identify.

Watson (2003) highlighted how within disability studies identity is often presented as fixed but he questioned whether such a shared identity exists. He interviewed 14 disabled men and 14 disabled women and found that many rejected impairment in the construction of their self-identity. Despite experience of oppressive practices, only 3 participants incorporated disability into their identity. For some this was because they rejected physicality as an essential, biological determinant of self. For others their self-identity was not about difference but what they could do. Ideas of normality, leading a normal life and just getting on with things were present in the majority of participants' responses. For others their identity involved a reconstruction of

normality in the construction of self-identity. Their self-identity as a normal person was not achieved through the sidelining of impairment but by reconstructing normality. Only a small number described themselves in negative terms. Watson's analysis suggested that having an impairment becomes part of everyday experience and simply a fact of life.

There are clearly areas of common ground to be found within disability studies and the sociology of chronic illness and disability, such as identity formation. However, disability studies grew in opposition to medical sociology and there remains today a marked divide in Britain between the two domains (Thomas, 2004²). More recent sociological studies have drawn inspiration from the interpretative tradition and have focused on how individuals make sense of disability and how their understanding influences social action. Disability theorists have been highly critical of such accounts as they adopt a personal tragedy approach to disability and locate the problem of disability within the individual (Barnes & Mercer, 1996).

Barnes and Mercer (1996) noted that medical sociologists readily adopted the ICDH framework (WHO, 1980) for explaining how impairment or chronic illness creates activity restrictions (disability) and social disadvantage (handicap). This stands in sharp contrast to the outright rejection of the framework by disability theorists. At the centre of the dispute was the question of how far sociological accounts elevated impairment to the determining 'cause' of disablement. Disability theorists have argued that sociological accounts deflect attention away from disablement and have made no impact on removing disabling barriers. As Barnes and Mercer

(1996) noted, this left little common ground with disability theorists and their concentration on the social exclusion and oppression of disabled people.

In spite of the unity of disability theorists in their critique of sociological accounts, recent years have seen the social model of disability being challenged from within the ranks of the Disabled People's Movement (Barnes & Mercer, 1996). Disabled feminists have been particularly critical of its failure to categorise the role played by impairment and illness in the life experiences of disabled people (Morris, 1991; French, 1993; Crow, 1996; Thomas, 1999). It is also suggested that the social model places too much emphasis on socio-structural barriers and consequently downplays the cultural and experiential dimensions of disability (Thomas, 1999). Shakespeare and Watson (1998) argued that a balance needs to be struck between understanding disabled people as individuals and as members of a disadvantaged group and hence to both recognise commonalities and respect differences. The social model is further criticised for its exclusion of particular groups including disabled children and young people (Shakespeare & Watson, 1998; Thomas, 1999; Connors & Stalker, 2007).

It could be further argued that the social model excludes those with a chronic illness. Marks (1999) noted that in an attempt to avoid the medical criteria associated with the nature of impairment, the social model argues a key criterion for inclusion in the Disabled People's Movement is to have a positive identity as disabled. However, many people with impairments and chronic illnesses do not necessarily identify as disabled. As someone with a chronic illness herself De Wolfe (2003) argued that there is a divide within disability studies between disability

and illness, with social responsibility for the latter construed mainly in terms of provision of individual health care and personal support. However, she believed it is not possible to draw a firm line between those characterised as disabled and those characterised as sick and she stressed the need for allegiances to be formed between the two. In acknowledgment of this the present study will draw upon literature and research that addresses the experiences of both young people described as disabled as well as those who have a specific chronic illness.

Disability activists are wary of any shift in perspective that might suggest a return to the traditional personal tragedy view of disability but the experience of illness and disability are often inextricably linked (De Wolfe, 2003). Disability activists construe their bodily state primarily as the subject of social accommodation rather than medical attention. The same cannot be said of people with chronic illness as many rely on medical attention to keep themselves well and in some cases alive. For those with chronic illness many problems do result from their bodily conditions and no amount of social accommodation can compensate for this (De Wolfe, 2003). However, De Wolfe stressed that this does not mean social arrangement does not have a significant impact on the experience of illness. It does not mean that people with chronic illness do not experience disability in the form of social barriers. Crow (1996) highlighted the political danger of neglecting embodied experience in that it may create a hierarchy of impairment headed by those whose impairments can at least in principle be rendered irrelevant by social change.

Thorne & Paterson (2000) have argued that the theoretical and pragmatic distinction between chronic illness and disability is a critical issue requiring wide spread consideration. At present

there is no political movement of sick people but it should be acknowledged that those who live with illness require social recognition, inclusion and support. This is unlikely to be forthcoming if illness, as has traditionally been the case with disability, is construed as a purely individual problem. De Wolfe (2003) is of the opinion that those with chronic illness would gain from a broadening of the Disability Movement to specifically include them as they could then begin to articulate their social needs. Disabled people could also benefit in feeling free to include all of their lives, as advocated by disabled feminists.

A social relational approach to disability as advocated by Thomas (1999) may go some way in addressing criticisms of the social model, in particular by being inclusive of all people who are disabled regardless of their particular impairment and thereby forging links between disability and illness. Thomas (2004²) stated that a social relational view of disability can be found within the original UPIAS (1976) manifesto however, she argued that this has been obscured by the shadow of the social model.

A social relational view means it is possible to acknowledge that impairment and chronic illness directly cause some restrictions of activity and Thomas (1999) referred to these as impairment effects. Impairment effects do not constitute disability as disability only comes into play when restrictions of activity are socially imposed (Thomas, 2006). Thomas (2001) stressed the importance of taking account of people's personal experiences of living with impairment. An enriched understanding of a variety of impairments may allow for many forms of disablism to be identified, understood and challenged (Thomas, 2001).

Thomas (1999) provided a social relational definition of disability:

“Disability is a form of social oppression involving the socially imposed restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being” (p.156).

Thomas (1999) recognised the role of socio-structural barriers in disabling people with impairment and referred to these as barriers to doing. However, she believed that other dimensions of disablism should move centre stage in disability studies – those that operate to shape personal identity and subjectivity and operate along psycho-emotional pathways. This she termed the psycho-emotional dimension of disability, which creates barriers to being. This form of disability can shape in a profound way what people can be as well as affecting what they can do as a consequence (Thomas, 2004¹). The agents of psycho-emotional disablism may be people close by such as family and friends, individuals in direct contact such as professionals or strangers (Thomas, 2001). A social relational approach may provide a more accurate account of disability for those with less visible impairments, including those with chronic illness, as whilst structural disablism may be present at some time in their lives the experience of psycho-emotional disablism may have a greater influence on their well being (Reeve, 2004).

Thus Thomas also emphasised the psychological effects of impairments and the review now turns to research from a psychological perspective.

2.4 Psychological approaches to chronic illness

2.4.1 Health psychology

Health psychology is considered to be closely related to the field of medical sociology as both disciplines study many of the same topics. However, they also differ in fundamental ways, namely in their theoretical underpinnings and thus their orientation to research (Umberson, 2000). The greatest overlap in the two fields occurs in the interest of both in psychosocial research and both fields view health and illness as the result of a complex interplay between biological, social and psychological factors. Within psychological approaches to health and illness emphasis is placed on individual factors such as personality traits and locus of control. Psychological approaches do recognise that the social environment affects the experience of health and illness but the focus is often on individual differences in reaction to the social environment (Umberson, 2000).

Health psychology emphasises the role of psychological factors in the cause, progression and consequences of health and illness (Ogden, 2004). A major focus within this field is health beliefs and behaviours. Studies with lay people have explored the complex and elaborate beliefs that individuals have about health. One concept to be developed from such research is health locus of control. Individuals differ as to whether they tend to regard events including those related to health as controllable by them (an internal locus of control) or uncontrollable by them

(an external locus of control). Locus of control has been shown to be related to whether an individual changes their behaviour for health reasons (Ogden, 2004).

The health belief model is a cognitive model developed by Rosenstock (1966) that is used within health psychology to predict preventative health behaviours and to understand the behavioural response to treatment in chronically ill patients. The model predicts that behaviour is a result of a set of core beliefs, these are: susceptibility to illness; severity of illness; the costs involved in carrying out the behaviour; the benefits involved in carrying out the behaviour; health motivation; perceived control and cues to action which may be internal or external. These core beliefs are used to predict the likelihood behaviour will occur (Ogden, 2004).

The review will now turn to psychosocial research on chronic illness in the areas of adjustment, coping and adherence.

2.4.2 Adjustment

Chronic diseases carry important psychological and social consequences that demand significant psychological adjustment and researchers have yielded complex conceptions of what it means to adjust to chronic disease (Stanton, Revenson & Tennen, 2007). Three broad conclusions have emerged from the literature on adjustment to chronic disease: chronic disease requires

adjustment across multiple life domains; adjustment unfolds over time and there is marked heterogeneity across individuals in how they adjust to chronic illness. Disease severity and prognosis, rapidity of health decline and whether the disease includes symptomatic or asymptomatic periods all operate to shape the adaptive tasks of illness (Stanton *et al.*, 2007).

Traditionally research about the relationship between psychological adjustment and physical illness has focused on psychological symptoms such as anxiety and depression (Walker, Jackson & Littlejohn, 2004). Adjustment is most commonly defined as the presence or absence of a psychological disorder, psychological symptoms or a negative mood (Stanton *et al.*, 2007).

Research on adjustment to chronic illness is usually measured through standardised instruments (Woodgate, 1998) such as psychological tests and quality of life measurements and conclusions are formed solely from this (Palmer & Boisen, 2002). The use of such measurements may only reveal part of the story of how individuals adjust to chronic illness, and Walker *et al.* (2004) have argued that in addition to psychological constructs biological and social constructs also need to be considered.

The limited literature that is available on the adjustment of both adolescents and adults with CF and other chronic illnesses has provided varied and conflicting perspectives (Palmer & Boisen, 2002). Some studies have reported poor adjustment, high levels of emotional disturbance, strained relationships, social isolation, low self esteem, distorted body image and increased anxiety and depression (e.g. Boyle, di Sant'Agnes & Sack *et al.*, 1976; Mulherin & Fitzgerald,

1992; Sawyer, Rosier & Phelan *et al.*, 1995; Bywater, 1981; Smith, Gad & O'Grady, 1983; Moise, Drotar & Doershuk *et al.*, 1987; Tropauer, Franz & Dilgard, 1970).

Contrary to this other studies have reported no increase in psychosocial problems, appropriate psychological functioning, satisfying relationships, successful employment and independent daily functioning (e.g. Aspin, 1991; Blair, Cull & Freeman, 1994; Sheperd, Hovell & Herwood *et al.*, 1990; Sinnema, Bonarious & Van Der Laag *et al.*; 1988; Spirito, Russo & Masek, 1984; Cappelli, McGrath & Heick *et al.*, 1989¹; Kellerman, Zelter & Ellenberg *et al.*, 1980; Seigal, Golden & Gough *et al.*, 1990). Studies of people with CF using psychological assessment tools have found very few if any differences between them and their healthy peers (e.g. Blair *et al.*, 1994; Sheperd *et al.*, 1990; Spirito *et al.*, 1984).

Based upon research with cancer patients, Taylor (1983) proposed a theory of cognitive adaptation to threatening events, which, proposes that the adjustment process is, centered around three themes. The first theme is a search for meaning in the experience, which entails effort to understand the threatening event, why it happened and what impact it has had. The second theme is an attempt to gain mastery over the event in particular and over one's life more generally. The final theme is an effort to restore self-esteem through self-enhancing evaluations. Self-enhancement, that is finding ways to feel good about oneself, is not addressed by one particular cognition but in their work Taylor, Wood & Lichtman (1983) found social comparison to be the chief vehicle by which self enhancement occurred.

More recent studies on the adjustment of adolescents and adults with CF and other chronic conditions have focused on Quality of Life measures. Quality of life is a multi dimensional measure that integrates self reported physical, emotional and social functioning and well being. Quality of Life scores reflect the impact of disease related stressors and other life stressors in relation to psychological adaptation of the individual (Goldbeck, Zerrer & Schmitz, 2007).

However, as with previous studies on adjustment the results of those reporting Quality of Life are also varied and sometimes conflicting. Some studies have found that adolescents and adults with CF have relatively good quality of life and achieve similar scores to healthy populations (e.g. Szynder, Towns & Asperen *et al.*, 2005; Britto, Kotagal & Homung *et al.*, 2002). Wahl, Rustoen & Hanestad *et al.* (2005) found adults with CF to have a better Quality of Life than individuals from the general population. However, in contrast to this Sawyer, Reynolds & Couper *et al.* (2004) found the health related Quality of Life of children and adolescents with chronic conditions to be significantly lower than that of those in a community sample.

Gee, Abbott & Conway *et al.* (2003) administered their disease specific Quality of Life measure to 223 adolescents and adults with CF. They found that adolescents and adults with CF experience a progressive deterioration in the majority of Quality of Life domains as their disease severity increases. The exception to this was 'concerns for the future' as scores in this domain remained low irrespective of disease severity. They argued this suggests that concerns for the future are of particular salience to adults with CF throughout their lives.

A number of contributors to adjustment have been identified. Social resources are important, as most adaptive tasks require help from others. This includes emotional support, which can encourage positive health behaviours and minimise risky behaviour. Personality attributes have been the focus of much research on adjustment. How personality affects adjustment falls into two perspectives – personality as a risk factor and personality as a protective factor (Stanton *et al.*, 2007). Optimism is a stable personality characteristic that has been shown to be important in adjustment to chronic illness (Walker *et al.*, 2004).

Another contributor to adjustment is an individual's cognitive appraisal processes. Most theories of psychosocial adjustment to illness converge on the point that how individuals view their disease is a fundamental determinant of adjustment e.g. whether they perceive their illness to be a threat to their life goals (Stanton *et al.*, 2007). Finally a factor repeatedly implicated as influencing adjustment to chronic illness is coping (Walker *et al.*, 2004). Much of the work on adjustment to chronic illness relates to conditions arising in later life, unlike a condition such as CF which is present from birth.

2.4.3 Coping

The course of a chronic disease is not only determined by biomedical or genetic factors but also by the way the patient deals with their illness (Schussler, 1992). Most studies on coping have used Lazarus & Folkman's (1984) transactional model as a frame of reference. This model

proposes that coping with stress (including disease related stress) requires cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.

Coping responses have been categorised according to different typologies that allow for the categorisation of coping responses into two contrasting coping styles. A coping style refers to a person's inclination to respond to a range of stressful situations in a particular way, independent of the context (Boekaerts & Roder, 1999). Lazarus & Folkman (1984) distinguished two major theory based functions of coping. Problem-focused coping involves addressing the problem that is causing distress e.g. making a plan of action. Emotion-focused coping is aimed at ameliorating negative emotions associated with the problem e.g. engaging in distancing activities. In addition several researchers have identified additional functions of coping such as meaning-focused where cognitive strategies are used to manage the meaning of a situation e.g. making positive comparisons (Folkman & Moskowitz, 2004). Disease concepts and coping will interact with social parameters such as the presence and use of social support (Schussler, 1992).

For those with a chronic disease, emotion-focused coping is thought to frequently occur in persons who do not accept their illness or consider it uncontrollable. Problem-focused coping is thought to occur in patients who accept their illness or believe they may be able to influence it (Schussler, 1992). Abbott, Dodd & Gee *et al.* (2001) developed and validated a CF specific coping scale, which was then administered to 174 patients. They identified four distinct ways of coping with CF: optimistic acceptance; hopefulness; distraction and avoidance. Differences in

coping held relevance for treatment adherence as outlined below. Optimism was the coping strategy most frequently used to deal with CF. However avoidance strategies were also used considerably and were for some individuals their predominant way of coping.

In the literature on adult coping Boekaerts & Roder (1999) have noted how relatively consistent findings have been reported, with problem-based coping viewed more favourably than emotion-focused coping such as avoidance which is considered to be maladaptive. Contrary to this Schussler (1992) has argued that in order to conquer a disease a moderate level of denial (emotion-focused coping) appears necessary. Moderate denial would entail only certain aspects of diseases to be denied e.g. their threat potential or uncertainty.

Abbott (2003) has suggested that it now appears a naïve question to ask which coping strategies are adaptive/maladaptive and rather we need to ask which strategies are adaptive/maladaptive for a particular individual against a particular outcome. In reality individuals are likely to use a number of different strategies that serve to both focus attention towards and away from the problem (Abbott, 2003). Lazarus and Folkman (1984) also drew attention to temporal ordering and argued that different coping strategies may be differentially effective during different stages of a stressful episode

A limitation of many studies on coping is their sole reliance on coping questionnaires that lack situational detail and thus greatly limit the likelihood of capturing the multifaceted ways people

appraise different types of stressors and deal with them (Boekaerts & Roder, 1999). Such studies cannot tell us why a person selects a particular coping response in a particular context. It is suggested that to gain insight into the coping behaviour of chronically ill people it is crucial that both objective and subjective characteristics are considered (Maes, Leventhal & Ridder, 1996). To do so a broad range of methods should be used that may provide a more comprehensive and holistic understanding of the individuality and complexity of coping e.g. interviews (Persson & Ryden, 2006)

2.4.4 Adherence

The terms adherence and compliance have generally been used interchangeably within the published medical literature to refer to the extent to which patients follow their prescribed health care regime (Sawyer & Aroni, 2003). However, there are subtle differences between the terms. There is a similarity between the terms compliance and obedience, which has meant that compliance has become increasingly seen as inappropriate. Instead much literature currently uses the term adherence, which implies one's reasoned agreement with a treatment regime (Sawyer & Aroni, 2003).

Poor adherence to treatment is well documented for those with chronic illness, with approximately 50% not adhering to their prescribed treatment regime (Myers & Horn, 2006; Sawyer & Aroni, 2003). Adherence may vary depending upon patient perceptions, forms of

treatment and definitions of adherence (Myers & Horn, 2006). There has been little or no association found between seriousness or severity of illness and adherence for those with CF (Myers & Horn, 2006; Abbott, Dodd & Bilton *et al.*, 1994). However, studies have consistently shown adherence to vary with different aspects of the CF regime with overall high rates for medication and low rates for chest physiotherapy and vitamin supplements (e.g. Abbott *et al.*, 1994; Sheperd *et al.*, 1990; Myers & Horn, 2006).

CF patients have cited a number of reasons for poor adherence to chest physiotherapy including: being too busy; not being bothered; problems fitting it into their lifestyle; the perception it does not help; the physical consequences of doing it; patients believed they were well; patients believed the severity of their disease was less than others (White, Stiller & Haensel, 2007; Myers & Horn, 2006; Abbott *et al.*, 1994). In their study of CF patients Abbott *et al.* (1994) found that the lowest adherence rates occurred when there was no immediate risk or discomfort associated with poor adherence. They also found that adherence improves when the treatment provides immediate and recognisable benefits to the patients. They have argued the results of their study suggest that patients may use their immediate symptoms to inform their decisions of whether to continue or discontinue a treatment. Patients may therefore focus on the short term rather than long term benefits of treatment.

The way in which individuals cope with CF may also influence adherence to treatment. Abbott *et al.* (2001) conducted research to examine the relationship between coping styles and adherence. They found that optimistic acceptance and hopefulness were associated with greater

adherence to treatment in adolescents and adults with CF. Those who used distraction strategies to cope with their CF were more likely to partially adhere to treatments. Those who employed an avoidant coping style reported greater levels of non-adherence to physiotherapy and enzyme therapy.

Kettler, Sawyer & Winefield *et al.* (2001) have drawn attention to the high level of demand placed on patients by the day-to-day management of their CF regime, which is both complex and time consuming. Little attention has been given to young people striving to reach adulthood who are often struggling for independence whilst trying to manage their regime and Abbott *et al.* (1994) have suggested that it may be unrealistic to expect young adults with CF to adhere strictly whilst trying to strike a balance between their needs and their daily regime.

There is a general assumption of a direct relationship between adherence behaviour and improvement in health outcomes (Sawyer & Aroni, 2003). However, Abbott *et al.* (2001) have noted that the positive linear relationship between adherence and health outcomes in CF is only assumed not absolute. They acknowledged that individuals respond differently to treatment and complete adherence does not necessarily guarantee good health. They noted how the literature tends to place all of the responsibility for adherence on patients and their families yet they argued for some of the onus to be placed on health professionals who have a responsibility to provide evidence based information and help reduce the treatment burden for those with CF. It may be the case that total adherence is not necessary.

It is clear that adherence behaviours may be less than ideal for many reasons and patients will construct their own versions of adherence according to their personal worldviews and social contexts. Sawyer & Aroni (2003) have stressed the need for an approach based on a more accurate understanding of everyday human behaviour. Such an approach would be better served to inform clinical practice rather than merely conceptualising those patients who are less than ideally adherent as irresponsible and irrational.

Social psychologists have also conducted research in a number of areas that hold relevance for those with a chronic illness. The review will now look at 2 areas of social psychology that are thought to have particular relevance for those with a chronic illness. These are stigma and social comparison.

2.4.5 Stigma

Like sociologists, social psychologists have for a number of decades been interested in the issue of stigma and the causes of stereotyping, prejudice and discrimination. In the 1980's theory and research begun to challenge traditional perspectives on how stigma affects self-esteem. At the time a number of psychological theories predicted that members of stigmatised groups should have low self esteem. However, Crocker and Major (1989) argued that empirical research was unable to support such a prediction. They suggested that this discrepancy could be explained by considering the ways in which members of a stigmatised group may protect their self-concept.

They proposed this could be done in a number of ways: by attributing negative feedback to prejudice against their group; by comparing their outcomes with those of the in group rather than the out group and finally by selectively devaluing those dimensions on which their group fares poorly and valuing those on which their group excels.

They acknowledged that reactions of the stigmatised were not uniform and outlined a number of moderating factors that may influence the use of these self-protective strategies, including:

- Time since acquisition of the stigma – unlike those born with a stigmatising condition, those only recently stigmatised may lack the strategies of self-protection.
- Concealability of the stigma – those with invisible stigmas may face less prejudices.
However, attempting to pass as normal may deny them the use of self-protective strategies.
- Acceptance of negative attitudes towards the stigmatised group – those who internalise negative views may be at particular risk for low self-esteem.

- Responsibility for the stigmatised condition – individuals may be treated better if they are not perceived to be personally responsible for their condition.
- Centrality of stigma in self concept – for some individuals a stigmatising condition may be a central aspect of their self concept but for others it may hold little relevance for their identity (Jones, Farina & Hastorf *et al.*, 1984).

In recent decades psychologists have also begun to pay greater attention to the psychological effects of social stigma. Major & O'Brien (2005) noted how, traditionally, members of stigmatised groups are portrayed as passive victims. However, they have argued that whilst research has demonstrated that stigma does have negative consequences for the stigmatised it should be noted that individual characteristics also play a key mediating role in responses to stigma. They organised recent theory and research within an identity threat model of stigma. The model posits that responses to stigma are a function of cues in the immediate situation, collective representations of one's stigma status and individual characteristics. An individual will experience an identity threat when they appraise the demands imposed by stigma as potentially harmful to their social identity and do not have the resources to cope with such demands. Identity threat can lead to responses such as anxiety, which may in turn have implications for important outcomes such as self-esteem, academic achievement and health.

Major & O'Brien have noted that one of the major insights provided by a social psychological perspective on stigma is the huge variability across people, groups and situations in responses to stigma. They argued such a perspective is needed to understand the factors that may make people resilient or vulnerable to stigma and hence to improve the predicament of the stigmatised.

2.4.6 Social Comparison

As previously mentioned in section 2.4.2, Taylor *et al.* (1983) found social comparison to be an important process through which self-enhancement occurs for those with a serious illness. Social comparison is a social psychological process (Gibbons, 1999) that is widely acknowledged as a central feature of human social life (Buunk & Gibbons, 2007). Social comparison is the process of comparing oneself to others in order to evaluate some aspect of self. It allows individuals to draw conclusions about their own actual or potential characteristics on the basis of the characteristics of actual or imagined other individuals (Buunk, Gibbons & Visser, 2002). Social comparison among those with a chronic condition is considered to be a common event and in recent years a great deal of attention has been given to this process amongst people experiencing health problems (e.g. Bennenbroek, Buunk & Van Der Zee *et al.*, 2002; Tennen, McKee & Affleck, 2000; Dibb & Yardley, 2006).

Classic social comparison theory was originally outlined by Festinger (1954). Festinger proposed that people's opinions, attitudes and beliefs must have some basis upon which they rest

for validity. When no objective information is available people evaluate their ability and opinions by comparing themselves with others. Individuals prefer information about others who are relatively similar to them as this provides the most relevant information. Buunk & Gibbons (2007) have noted that in recent decades work on social comparison has undergone numerous transitions and refinements and has developed from the fixed theoretical statements originally proposed by Festinger into a lively, varied and complex area of research, encompassing a range of different paradigms, approaches and applications.

An important development in the evolution of social comparison theory was the emergence of downward comparison theory (Buunk & Gibbons, 2007). Wills (1981) proposed that people who feel threatened due to a decline in their well-being will often compare themselves with others thought to be worse off in an attempt to bolster self-esteem. A further version of downward comparison is for individuals to compare themselves with similar targets in order to reduce anxiety and isolation.

It has been argued that downward social comparison can be an important means by which, people with illness can maintain a positive view of their situation by focusing on dimensions in which they perceive themselves to be more fortunate or successful than others (Taylor, 1983). This has been demonstrated in the work of Taylor *et al.* (1983) with female cancer patients. Virtually all of the women interviewed thought they were doing as well if not somewhat better than other women coping with the same crisis. They were able to enhance their self-esteem through comparisons with those worse off than themselves. The need to come out of the social

comparison process appearing better off drove the process itself and if a person considered worse off was not available through personal experience then such a person was often manufactured.

Although such findings are considered strong and convincing it has since become evident that some people facing threatening events avoid making downward comparisons and prefer instead to make upward comparisons, that is to compare themselves with others considered to be better off (Buunk & Gibbons, 2007). In an effort to reconcile such contradictions Taylor & Lobel (1989) developed a model that can be used to describe the social comparison process for people faced with a serious health threat. They distinguished between two different modes of social comparison. The first is based on seeking information and contact with others, which may foster self-improvement. Here the individual will make upward comparisons with others undergoing similar experiences who are coping well. This can provide valuable information for successful coping and may induce hope, motivation and aspiration. The second mode is based on making relative evaluations to achieve self-enhancement. Here individuals will make downward comparisons with those they consider worse off in an attempt to feel better about their own situation.

Derlega, Roninett & Winstead *et al.* (2003) conducted research on the social comparison process for patients with diabetes and found their results to be largely consistent with Taylor & Lobel's model. Dibb and Yardley (2006) found that people with chronic illness carry out a wide range of forms of social comparison, including upward, downward and lateral comparison on illness and coping dimensions, as well as comparing solely for informational purposes. They also noted that

both upward and downward comparisons could have negative consequences for the chronically ill as well as positive consequences. This is consistent with the identification/contrast model developed by Buunk, Collins & Taylor *et al.* (1990), which, proposes that social comparison can result in both positive and negative effects. This is dependent on whether the individual has identified or contrasted with their comparison target.

2.4.7 Criticisms of psychological approaches to chronic illness/disability

Disability theorists have been highly critical of psychological approaches to disability/chronic illness. Thomas (1999) argued that the literature within social psychology is characterised by the individual, personal tragedy approach to disability, as it is preoccupied with issues of individual adjustment to, coping with and making the best of the misfortune of being disabled. It is increasingly argued by disability theorists that individual psychology is inadequate and unacceptable in explaining chronic illness and disability (Priestly, 1998).

Each of the approaches reviewed above have come under criticism for failing to account for the whole experience of living with disability or chronic illness. In order to understand the transition to adulthood for those with CF it is important to consider all aspects of their lives during this phase and not just those aspects specific to living with a chronic illness. For adolescents with CF, as well as issues relating to their condition, they will also have to deal with the same issues of the transition to adulthood as any adolescent and consequently the literature on adolescence is

relevant. The review will now provide a brief outline of the literature on adolescence and the transition to adulthood before turning to the literature that addresses this stage of life specifically for chronically ill and disabled young people

2.5 Adolescence and the transition to adulthood

2.5.1 Adolescence

Adolescence covers a number of years and it is difficult to define as it covers a lengthy developmental span. However, it is generally thought to begin at around 12 years of age and end around 18 years (Bukato, 2008). It is often described as a period of transition from dependent childhood to independent adulthood (Tyrell, 2001) but it is acknowledged that the boundaries and experiences of this part of the life cycle can be subject to considerable individual variation (Esmond, 2000).

Adolescence is a time of biological, cognitive, social and emotional development. Biologically adolescence begins when the individual enters puberty. Puberty brings extensive changes to the body and modifies how young people think about themselves and how others interact with them (Santrock, 1998).

With cognitive development adolescents refine their thinking and move through a number of cognitive milestones. Piaget's theory states that individuals develop through four main cognitive stages and by the time an individual has reached adolescence they will most likely have moved into the final stage, the formal operational stage (Inhelder & Piaget, 1958). At this point adolescents' thinking is both logical and abstract and they are able to engage in hypothetical reasoning. This represents a shift in thinking from the real to the possible.

Social cognition refers to how individuals conceptualise and reason about their social world. Elkind (1976) developed the notion of egocentrism in adolescence. Egocentrism refers to the heightened self-consciousness of an adolescent. This is split into two types of thinking: the imaginary audience and the personal fable. The imaginary audience refers to the adolescent's belief that others are as interested in them as they themselves are. This involves attention-seeking behaviour. The personal fable refers to the adolescent's belief that their concerns and feelings are unique which, makes them feel that no one else can understand how they really feel.

Adolescence is a time when individuals begin to form a solid sense of identity, a fuller sense of awareness and greater feelings of confidence (Bukato, 2008). During adolescence the self as a concept begins to be viewed from multiple and even opposing perspectives. The ways in which young people understand and perceive themselves greatly affects their subsequent reactions to various life events. The young person who wants to be integrated into society faces the dilemma of striking a balance between playing appropriate social roles whilst maintaining elements of individuality. During this stage an individual's self esteem, that is their sense of self worth is

thought to be important as a barometer of coping and adaptation. Research has consistently demonstrated that low self esteem is likely to be predictive of adjustment difficulties and that those with high self esteem do relatively well in a variety of domains (Coleman & Hendry, 1999).

Erikson (1968) has provided a comprehensive theory of identity development. He viewed life as a series of stages with the fifth stage being identity versus identity confusion. This stage occurs during the adolescent years as individuals examine who they are, what they are about and where they are going in life. Psychosocial moratorium is the term used by Erikson to describe the gap between childhood security and adult autonomy that adolescents experience as part of their identity exploration (Santrock, 1998). During this time adolescents try out different roles and personalities before reaching a sense of stable self. Youths who successfully cope with these conflicting identities are said to emerge with a refreshing and acceptable sense of self. Those unable to resolve this identity crisis suffer identity confusion and will consequently either withdraw and isolate themselves from friends and family or immerse themselves in their peers and lose their identity in the crowd.

The developmental changes of adolescence occur within a variety of contexts including both families and peers. The development of independence or autonomy, in respect of family relationships is a key task for adolescents (Coleman & Hendry, 1999). This typically precipitates a change in parent-child relations as adolescents push for independence and parents are required to adjust to form more egalitarian relationships with their children. Communication with parents

will change at this time and it is common for conflicts to increase (Bukato, 2008). However, families continue to play an important socialising role throughout the adolescent years (Santrock, 1998).

The nature of peer relationships also undergo important changes during adolescence and most adolescents will spend a considerable amount of their free time with peers. As they seek to grow more independent of family, peer groups and friendship groups become an important point of reference in social development. Peers can provide the social context for shaping the day-to-day behaviours of adolescents and can encourage conformity to standard norms and values. Young people often use risk-taking behaviour to identify with adult patterns of behaviour and adolescents may be particularly prone to taking health risks (Hendry, Shucksmith & Lowe *et al.*, 1993).

Adolescents typically prefer to have a smaller number of friendships that are more intense and intimate than those of younger children. Such friendships are normally formed with a subset of peers who resemble themselves in certain characteristics. Many adolescents will also form cliques, these are groups of five to ten who frequently interact with each other. Peer relations in adolescence also involve larger networks as adolescents begin to identify and hang out with a particular crowd, that is larger groups of peers with a specific reputation (Bukato, 2008). At some point during adolescence, individuals are also likely to become interested in romantic relationships (Santrock, 2008). Due to the centrality of peers in the adolescent's social life peer

acceptance is hugely important and for those that don't achieve this it can be a time of loneliness and social isolation (Coleman & Hendry, 1999).

2.5.2 The transition to adulthood

Adolescence is the time when young people begin to make the transition from childhood to adulthood. Transition in UK culture tends to begin around the age of 16 years and continues into the early 20's (Barnados, 1996) and it can be a complex and difficult time for many young people. Role transitions are regarded as integral to the attainment of adult status. These are concrete steps largely defined by social and official norms of independence (Westberg, 2004). Within Western societies the transition to adulthood is typically thought to comprise of the following role transitions:

- Transition from school to higher education/employment.
- Leaving the family home to set up a new independent home.
- Becoming involved in sexual relationships and eventually cohabitation or marriage.

- Becoming a parent for the first time.
- Achievement of financial independence.
- Becoming a full adult consumer (Barnados, 1996; Morrow & Richards, 1996).

The term transition to adulthood implies a beginning and end point with the move from relative dependence to relative independence. However, in recent years this phase of life is thought to have become increasingly more complex with less clear-cut beginning and end points (Westberg, 2004). Morrow & Richards (1996) have identified a number of changes. Many young people expect autonomy and independence at an early age but social and political changes mean they are often dependent on their families for a longer period than previously. More young people now remain in higher education or training thus delaying their entry to the adult labour market. This delays the achievement of financial independence meaning many young people leave home at a later age. Young people are now entering sexual relationships earlier but are marrying/cohabiting and having children later.

2.6 Adolescence and the transition to adulthood for chronically ill/disabled young people

Transition to adulthood is a major milestone only recently actualised for young people with a chronic illness such as CF. Increasing survival rates have opened up the possibility for many young people with conditions such as CF to achieve the major milestones of adulthood i.e. completing higher education, achieving full time employment and establishing their own independent families (Badlan, 2006).

Adolescents and young adults with chronic conditions are likely to have the same developmental, emotional and social needs as their healthy peers and to desire as normal a life as possible (WHO, 2002). As life expectancy has increased young people with CF should be looking forward to adulthood, expecting to grow up and be prepared for what lies ahead (Tyrell, 2001). The reality though is that for many young people living with previously fatal conditions the transition to adulthood means going where few have gone before, without any hint of what they may anticipate along the journey (Blum, 2005). White (1997) has previously argued that the focus of healthcare needs to shift from survival to understanding how to help young people with chronic illness make the transition to adulthood, be independent and successful and become contributing adults in society.

There is a general consensus within the literature that having a chronic illness/being disabled adds a further dimension to adolescence and presents additional and unique challenges in the transition to adulthood (Betz & Redcay, 2002; Boice, 1998; Palmer & Boisen, 2002; Shultz &

Liptak, 1998; Tyrell, 2001; Woodgate, 1998). Consequently, young people with chronic conditions may face more difficulty negotiating the developmental tasks of adolescence than their healthy peers (Yeo & Sawyer, 2005). The extent of difficulty faced will be influenced by both the nature of the impairment and wider social and political factors (Riddell, 1998). The wide variation in disease severity for CF makes it likely there will be much variation in the way CF impacts on adolescence, requiring different levels of adjustment to lifestyle and long term goals (Blum, 1991).

In spite of this consensus it has been noted that much of the literature about transition for these young people is primarily descriptive (Stewart, Law & Rosenbaum *et al.*, 2001). There is a lack of work providing insight into how the dynamics of the transition to adulthood operate for this group of young people (Riddell, 1998). The literature that is available suggests that chronic illness can have significant consequences within a broad range of life domains (Blum, 1992; Eiser, 1993) and can affect physical, cognitive, social and emotional spheres of adolescent development (Yeo & Sawyer, 2005). Hendey & Pascall (2002) found that young disabled people have similar aspirations for adulthood as their peers such as paid work, independent living and social relationships. However, having a chronic illness may present young people with a number of significant barriers to the transition to adulthood including: health care obstacles; barriers to education and employment and barriers to independent living (Betz & Redcay 2002).

Chronic illness can cause delayed puberty and this as well as any other visible signs of illness may result in the young person feeling different from their peers (Boice, 1998). Consequently

the young person may not feel accepted by their peers, which can result in social isolation and low self esteem (Badlan, 2006). Even if the chronic illness is invisible Blum (1991) has argued that feeling different from peers is equally if not more isolating than looking different. Chronic illness may therefore have a profound impact on a young person's identity. Adolescents with a chronic illness may enjoy relationships with peers in a similar situation to themselves as this can provide a sense of community and enable them to share illness related things such as fears and coping strategies (Tyrell, 2001). However, for those with CF such opportunities are severely restricted due to the risk of cross infection.

Chronic illness may also impact upon family dynamics. It is expected that young people will begin to take greater responsibility for their own health care during adolescence to mirror normal adolescent growth and development (Blum, 1991). However, it can be difficult for parents to relinquish control. Adolescents may find the achievement of autonomy more difficult than their healthy peers (Boice, 1998). For example, an adolescent with CF may be keen to gain independence from their family but then find themselves dependent upon them in times of deteriorating health (Blum, 1991).

Most adolescents with chronic illnesses such as CF attend mainstream schools by virtue of the 1981 Education Act (Tyrell, 2001). However, recurrent illness and treatment regimes can have a significant impact on school attendance (Suris, Michaud & Viner, 2004). In spite of this many adolescents with a non-cognitive impairment and their families, do not want to be identified as having special educational needs and consequently do not receive specific provisions through a

statement (CF Trust, 2004). This can mean they receive a limited amount of support and services even though they may need them (White, 1997). Chronic illness may also impact on a young person's choices for higher education. If a young person with CF wanted to move away to university they would most likely have to make sure they would have access to a specialist CF centre (WHO, 2002).

Finding employment is considered crucial to achieving financial independence (White, 1997). Having a chronic illness can make it difficult for young people to find and maintain employment (Yeo & Sawyer, 2005). Many adults with CF have major physical and psychological impediments to maintaining continuous employment. The progressive nature of the condition means they are confronted with difficult decisions regarding work participation (White, 1997). Those with CF would require a flexible employer and a suitable working environment (CF Trust, 2003).

For a person with CF the adolescent years are often the time when health begins to deteriorate and they are consequently asked to adhere to a time consuming treatment as well as take greater responsibility for their own care (Tyrell, 2001). The potential amount of time spent on treatment is enormous and perhaps unsurprisingly adolescence is a time when many rebel against their treatment. Consequently, parents may be reluctant to allow their child to function independently for fear they may make choices that compromise their health (Tyrell, 2001).

From the adolescent's perspective, treatment can serve as a daily reminder of their difference to peers, of the disease itself and the threat of premature death (Blum, 1991). Other developmental priorities such as establishing an identity and developing social relationships can compete with the demands of health care. Blum (1991) has argued that to see poor adherence at this time as an inevitable symptom of adolescent rebellion is a broad and simplistic generalisation, particularly as poor adherence also occurs in adults. Tyrell (2001) stated that flexibility and honesty are key to enhancing adherence during this time as the young person needs to be allowed to make their own choices. Taking greater responsibility for their own illness is important preparation for the transition from pediatric to adult health care. The transition to adult health care is a transition that young people with chronic illnesses must contend with in addition to all the other tasks of the transition to adulthood. This is addressed in section 2.7.

Shay & Newth (1985) proposed a number of CF specific developmental tasks that the person with CF must accomplish in addition to the normal tasks of adolescence and adulthood, these are:

Adolescence:

- Deal with rebellion/defiance to treatment.

- Cope with a sense of difference and isolation from peers.
- Build confidence and self-respect.
- Learn to set appropriate goals.
- Establish normal relationships

Adulthood:

- Set educational/occupational goals.
- Preserve employment despite discrimination.
- Develop motivation to achieve.

- Establish intimacy with a partner.
- Consider parenthood in light of genetic facts.
- Learn to live alone while coping with the treatment program.
- Adjust to the need for dependence if health fails.

This model was developed at a time when life expectancy was much lower than it currently is and consequently fewer people with CF survived into adulthood. It is therefore anticipated that the current concerns and experiences of the CF population may differ somewhat to those outlined above, something the present study aimed to establish.

The transition to adult health care is a transition that young people with chronic illnesses must contend with in addition to all the other tasks of the transition to adulthood. The review will now focus on this specific transition and published work from both within the UK and at an international level.

2.7 Transition from paediatric to adult health services

The transition from paediatric to adult health services for young people with CF, as with many other chronic illnesses, has only become necessary in the last 20-30 years. Treatment advances in recent years mean many more young people with CF are surviving into adulthood and this increased longevity has necessitated the development of new services to meet adult needs (Pownceby, 1995). It has now become apparent that in CF with increasing age comes a whole host of additional medical issues such as osteoporosis and infertility and social issues such as disclosure of the condition, which many believe the paediatric team are not best equipped to deal with (Lowton, Mathes & Wyall *et al.*, 2005).

As noted earlier adolescence is commonly perceived as a time of major physical and psychological change and Conway (1998) stated that an overriding aim of professional health carers must be to encourage patients with CF to confront the problems of adolescence and help maintain physical and emotional stability. He stressed that a planned and sensitive transition to adult health care should aid the successful evolution to adult life. The development of transition has been one of the major challenges of the 21st Century (McDonagh, 2005), which is hardly surprising given that this period is probably one of the most important CF relevant milestones in family life since diagnosis was first discussed with parents (Conway, 1998).

2.7.1 Definitions of transition

It is important to differentiate between the terms transfer and transition both of which are commonly used in the literature. The term transfer is used to describe the handover from paediatric to adult services (DoH, 2006) and is therefore, merely the point in time when care begins in the adult setting (McDonald, 2000). There is a broad consensus throughout the literature that handover should be planned and managed as a process and as such the term transition is more appropriate (DoH, 2006). A frequently cited definition of transition is:

“The purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult orientated health care systems” (Blum, Garell & Hodgman *et al.*, 1993).

Blum (1995) stated that the optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive. However, transition is commonly regarded as much more than the move to adult health care. Rather it is a multi dimensional process that involves other important areas of the young person’s life such as education, independent living and community inclusion. It is felt that transition to adult health care will facilitate, or at the very least, affect transition in these other areas (Geenen, Powers & Sells, 2003). Therefore, it is clear that a core element of transitional care must be the provision of services, which reflect the changing status and outlook of the young person.

Ultimately it is felt a carefully planned transition to adult health care should improve self-reliance, enhance autonomy and independence and support young people in attaining their maximum potential and meaningful adult lives (Rosen, 1995). Soanes and Timmons (2004) described transition, as a process that attends to the medical, psychosocial and educational needs of young people with chronic illness as they transfer to adult orientated care.

There now appears to be a general consensus amongst health professionals that developmentally appropriate treatment should be provided to young people with chronic illness in adult facilities (Soanes & Timmons, 2004). However, a recent study in the US revealed that 20% of adults with CF continued to be cared for by a paediatrician (Flume, Taylor & Anderson *et al.*, 2004).

Paediatric teams are used to communicating through parents and the philosophy of care is often prescriptive and protective (Madge & Bryon, 2002). By staying within the paediatric environment the young person may continue to be perceived as a child; yet they need to be encouraged to take decisions, make life plans and be helped to live and work in the world as it really is (Conway, 1998). It is important that young people with CF are given a clear sign that it is possible to have a positive future with expectations of a long survival. Conway has argued that keeping them in a paediatric clinic is tantamount to telling them their lives will be too short to warrant the bother of moving.

Often the problem is that adolescents sit poorly between the family centered, developmentally focused paediatric paradigm and the adult medical culture, which acknowledges patient autonomy but neglects growth, development and family concerns. However, a sensitive and

coordinated transition program can help to bridge this gap and prepare the young person for both adult health care and adulthood in general (McDonald, 2000).

Morris (1999) stressed that the way in which young people transfer from child to adult services will to a large extent determine the nature of their access to health services throughout most of their adulthood. Transition to adult health services for young people with CF within the UK is to date seriously under-funded. Although the number of transition services is increasing the picture across the country is still patchy and Conway (2004) stated that we have some way to go in achieving a high universal standard of transitional care for young adults with CF. At present the role of coordinating the move between services has largely fallen to the CF nurse specialist (Cowlard, 2002).

2.7.2 Transition policies and programmes

It would appear that the issue of transition is now beginning to receive far more attention and the UK is currently undergoing a period of major policy development in health, social services and education. A number of recent government policies, papers and reports impact directly or indirectly upon the issue of transition and adolescent health (McDonagh, 2006) including: The National Service Framework (DoH, 2004); Every Child Matters (DfES, 2004); Our Health, Our Care, Our Say (DoH, 2005¹); You're welcome quality criteria. Making health services young people friendly (DoH, 2005²); Youth Matters (DfES, 2005); Transitions: Young Adults with Complex Needs (ODPM, 2005).

The National Service Framework (NSF) is a ten-year program that sets standards for child health and social services (DoH, 2004). Standard four states that all young people should have access to age-appropriate services, which are responsive to their specific needs as they grow into adulthood. It goes on to state that transition to adult services for young people should be planned and coordinated around the needs of each young person to maximise health outcomes, life chances and opportunities to live independently. A vision of the NSF is that all transition processes are planned in partnership and focused around the preparation of the young person. It highlights that all paediatric clinics should have a written policy on transition to adult services, which is the responsibility of a named person.

Following the NSF a good practice guide was published entitled Transition – Getting It Right (DoH, 2006). The guide recognised that transition to adult services can impact upon clinical, educational and social outcomes for young people and strongly advocated the use of transition planning and programmes.

In addition to the national documents outlined above documents of relevance to transition and adolescent health have been published by professional bodies in the UK (McDonagh, 2006): Getting it Right for teenagers in your practice (Royal College of General Practitioners and Royal College of Nursing, 2002); Adolescent Transition: Guidance for Nursing Staff (Royal College of Nursing, 2004); Bridging the Gap: Health Care for Adolescents (Royal College of Paediatrics and Child Health, 2003); Adolescent Health (British Medical Association, 2003). The Bridging the Gap document highlighted the need for health services to pay greater attention to the specific

needs of adolescents whilst the Adolescent Transition document provided specific guidance for nursing staff on transition planning including the key issues of transition and providing effective transition services.

Specific to CF, the CF Trust (2001) has published Standards for the Clinical Care of Children and Adults with CF. The general focus of the document is on the need for specialist care for those with CF and the ways in which this can be provided. It provided a framework for the commissioning of CF services to ensure that uniformly high standards of care are available throughout the country. The document is used as a basis for clinic accreditation to highlight the standards required (CF Trust, 2001). In addition the CF Trust also provides literature specific to the issue of transition. Fact sheets on transition are available for young people, parents and commissioners and hospital and clinical teams (CF Trust, 2006, ¹⁻³).

On an international level the Canadian Paediatric society (2006) has recently published a position statement on the care of adolescents with chronic conditions, which addresses transition and transfer of care. The American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine (2002) have jointly published A Consensus Statement on Health care Transitions for Young Adults with Special Health Care Needs. This document has been approved as policy and outlines basic guidelines for health care transition.

At present transition program descriptions are found primarily in the medical literature with emphasis solely on medical services transfer (Betz & Redcay, 2003). Transitional service models in health care settings are in the seminal stages and currently in the UK no single model of transition has been adopted as standard (Soanes & Timmons, 2004). Despite the existence of several different models of transitional care as yet there is no research to say which, is the best. All CF centre's must follow CF Trust (2001) guidelines but adapt them to serve their own communities (Lyon, 2003).

A number of key elements of transitional care have been highlighted by both US and UK policy makers and many of these elements are supported by evidence from recent studies. Viner (1999) identified 6 key elements of transitional care: timing; preparation; coordination; capable adult service; administrative support and primary care involvement.

1. A policy on the timing of transfer

Viner stated there is no right time for transfer of care and that flexibility is very important. However, he stressed that a target age is useful. The CF Trust (2006, ³) suggested a broad age limit for transfer of 14-18 years. In a UK study of 104 young people with CF, the wide age range spanned by those who felt they were transferring at the right time would appear to advocate flexibility (Pownceby, 1995). It is generally felt that an arbitrary age point assumes that

chronological age alone indicates readiness to transfer and this disregards the complexity of adolescent development (While *et al.*, 2004).

It has been suggested the use of a form of readiness assessment other than age could be used, for example, the transfer questionnaire developed by Cappelli, McDonald & McGrath (1989²). Betz (1998) identified a number of proponents to be considered in the assessment of a patient's readiness to transfer. These are: readiness to assume responsibility for treatment management; previous involvement in managing treatment regime; demonstration of independent and responsible judgement; previous response to emergency situations; ability to seek solutions to problems; ability to cope with condition; identification of self as an individual with a chronic illness; relationship with paediatric provider; attitude of paediatric provider to transition; extent to which developmental issues have been addressed.

2. A preparation period and education program: identification of a necessary skill set to enable the young person to function in the adult clinic

Viner argued that transition should not occur before the young person has the skills and education to manage their illness largely independent of parents and staff. It is commonly thought that transition should be discussed with patients and their families from an early stage and that the prospect of transfer should be introduced at least one year prior to the event to allow young people time to express their feelings and resolve any concerns (Cowlard, 2002; Conway,

2004). Throughout the whole transition process emphasis must be placed on the preparation of the patient and family (McDonald, 2000) and there should be a gradual change of emphasis on responsibility from parents to young people (CF Trust, 2006³). The transition process should address various relevant issues, which can provide a focus for discussion and encourage movement.

Patterson and Lanier (1999) explored the views of adolescents with special health care needs and concluded that a useful strategy for transition was for the teen to become an expert on their own health condition. Madge and Bryon (2002) found that 62% of young people with CF look forward to taking control of and managing their own health condition. Pownceby (1995) reported that young people with CF thought it would be helpful to have a longer period of preparation and to begin seeing the doctor on their own prior to transfer. A number of studies have reported that young people want more and better information throughout the transition process (Bywater, 1981; Steinbeck & Brodie, 2006; Pownceby, 1995).

3. A coordinated transfer process

A key theme throughout the literature is that young people should be offered the opportunity to visit the adult clinic and meet the staff there prior to transfer (McDonald, 2000). Pownceby (1995) found that a large number of the young people studied had visited the adult centre prior to transfer and felt it had been useful. Boyle, Farukhi & Nosky (2001) found that there were higher

levels of concern expressed in all areas by young people with CF who had not met the adult team prior to transfer. The CF Trust (2006, ³) also strongly advocates the setting up of joint transition clinics whereby the young person and their family get to meet with both the paediatric and adult team together prior to transfer. Both Pownceby (1995) and Westwood, Henley & Willcox (1999) reported that over 90% of the CF patients in their studies felt a joint transition clinic would be a good idea. However, Pownceby also noted that less than half of the post transition group had been given the opportunity to attend one.

Another core element of transitional care expressed in the literature is that a key person from the paediatric centre should facilitate the introduction to adult services and provide emotional support throughout the transition process (CF Trust, 2006, ³). Por, Goldberg & Lennox *et al.* (2004) found that many health professionals were in agreement over the need to identify a named professional. This responsibility often falls to the CF nurse specialist as it is felt their role is integral to planning and coordinating transition services (Cowlard, 2002).

4. An interested and capable adult service

A transition program can only be successful if it is organised with the active participation and interest of the adult staff (Viner, 1999)

5. Administrative Support

Viner stressed the need for paediatric clinics to develop a formalised transition checklist. It has been stressed that young people should have an individual transition plan and case management specific to their needs (Betz, 1998; Steinbeck & Brodie, 2006).

6. Primary Care involvement

Transition planning should involve primary care physicians who may provide the only continuity of health care for young people at this point. However, it is often the case that many young people with chronic illness have little or no involvement with their general practitioner (Viner, 1999).

In addition to the above key elements research with young people and their families has shown that they want to be involved in transition planning (Madge & Bryon, 2002) and would like the transition process to be a more holistic one (Geenen *et al.*, 2003). Scal (2002) found that primary health care professionals do feel it is equally important to address the medical, behavioural and social issues in transitional care and to see transition as more than the transfer of care.

2.7.3 Barriers to transition

Barriers to successful transition have been extensively documented in the literature and they are also supported by evidence from recent studies. Conway (2004) noted that many of the obstacles currently identified in the literature are the same ones that were being identified a decade ago. McDonald (2000) identified a number of potential barriers that arise from the following areas: patients and families; paediatric providers and adult providers.

- Patients and their families

McDonald noted that there is often a strong bond formed with the paediatric team and a real fear of the unknown for young people and their families. It seems inevitable that young people will feel apprehensive about leaving behind the carers who they may have known all their lives. They may have to move to a new hospital and meet a whole new team who do things very differently (Lyon, 2003). In a number of studies young people have identified leaving behind paediatric caregivers and getting to know and trust a new staff team as a barrier to transition (Patterson & Lanier, 1999; Boyle *et al.*, 2001; Cowlard, 2003).

Studies in Australia (Steinbeck & Brodie, 2006; Brumsfield & Lansbury, 2004), the US (Boyle *et al.*, 2001; Patterson & Lanier 1999), the UK (Pownceby, 1995; Soanes & Timmons, 2004),

and South Africa (Westwood *et al.*, 1999) have all highlighted that transition to adult health care is an issue of concern and a challenging time for many young people with chronic illness. Telfair, Myers & Drenzer (1994) found young people had very mixed emotions about the transfer. However, in contrast a study of 334 adults with CF found they had no significant concerns about transferring their care (Anderson, Flume & Hardy *et al.*, 2002). However, the authors recognised the potential bias of the study as the sample only consisted of members of the International Association of Cystic Fibrosis, who may be particularly motivated.

The attitudes of patients and their families will clearly have a great impact on the process of transition. Flume, Anderson & Hardy *et al.*, (2001) issued a survey on the problems related to transition to team members at paediatric and adult CF centre's. Over half of the respondents cited patient and family resistance as a criteria precluding transfer. This perhaps suggests that paediatric team members are failing to communicate positively with patients and their families (Conway, 2004).

For parents the transition process can often signify a loss of control (McDonald, 2000). Parents may feel the adult team excludes them by giving young people greater freedom to care for themselves (Lyon, 2003). There is evidence of this from a number of studies (Reiss, Gibson & Walker, 2005; Patterson and Lanier 1999). Boyle *et al.*, (2001) found the most common concern of parents was the ability of the child to care for their CF independently - a concern not shared by their children. Pownceby (1995) also found that many young people with CF looked forward to being in an age appropriate environment and being treated in a more adult way.

- Paediatric providers

McDonald (2000) noted that the paediatric team will have invested a large amount of skill, expertise and care. They may be concerned that by transferring, the young person's health may be compromised. They may have difficulty perceiving the young person as an adult and become vulnerable to their pleas of extended stay. They may also have concerns about the skills and knowledge of adult providers.

- Adult Providers

Adult providers may not be used to dealing with adolescents and as they work within an individually focused model of medicine they may not be used to dealing with families (McDonald, 2000). Alarming, it is still the case that for some young people there simply isn't an adult service for them to be transferred to. In a US study of paediatric and adult CF providers almost 40% reported there was no specific adult program for young people with CF (Flume *et al.*, 2001).

2.7.4 Pitfalls of transition

McDonald (2000) identified a number of pitfalls to be avoided in the transition process:

- Sudden transfer of care without preparation. Pownceby (1995) found that one quarter of young people with CF did not know when they would transfer despite the fact they had been identified as likely to transfer in the next 2 years. Half of those who had already transferred stated they had not been involved in the decision process.
- Young people should not be transferred at a time of crisis or instability. The literature suggests young people should transfer at the point they are considered developmentally ready yet a study of CF team members revealed that 27% cited pregnancy and 16% cited marriage as criteria for transfer (Flume *et al.*, 2001).
- Transfer should not occur when end of life is imminent.

Research on transition has also revealed a great lack of continuity in the transition process.

Studies have highlighted a lack of standard transition procedures even within centre's (Brumfield & Lansbury, 2004; Anderson *et al.*, 2002; Pownceby, 1995). Pownceby (1995) pointed out that young people's experiences of the transition process in the UK may reflect differences in both

policy and practice. For some the process of transition is non-existent and this seems particularly evident in the US.

In 1981 a US study by Bywater revealed that 52% of young people with CF were not interested in transferring and only 43% had consented to transferring. It would seem that over two decades later the problem is still not resolved. Zack, Jacobs & Keenan *et al.*, (2003) conducted a study in the US of people aged 10-34 years with CF. Only 30% had consented to transfer while the other 70% had not, citing medical, personal and financial reasons. Anderson *et al.*, (2002) also found in their study of 334 adults with CF in the US and other countries including the UK that nearly one quarter were still receiving care from a paediatrician.

2.7.5 Gaps in research on transition

It is clear that the current literature on health care transition is primarily in the form of policy and position statements, program descriptions and suggested transition practices (Reiss *et al.*, 2005).

The majority of research that has been conducted has been through quantitative surveys.

Although the literature provides information about the barriers to transition and identifies promising practices a full understanding of the transition experience remains elusive (Reiss *et al.*, 2005).

More work is needed to examine the perspectives of young people, particularly in research specific to individuals with CF. So far research has concentrated predominantly on the opinions and practices of care providers (Boyle *et al.*, 2001). Forbes, While & Ullman *et al.*, (2002) state that what is missing is a more in depth account of what is actually said and done in the transition process from the perspectives of young people. By using a purely qualitative design and inviting young people with CF to speak openly and freely about their experiences of the transition process it is hoped the present study can provide a more in depth account than has so far been achieved.

It is evident that much of the published work on transition has been conducted in the US and Australia (Por *et al.*, 2004), although in recent years a number of studies have been conducted within the UK. The present study will differ from those published in the UK, which have tended to focus on evaluation of a specific service (Cowlard, 2003), concentrated on the perspectives of health professionals (Por *et al.*, 2003), used quantitative methods (Madge & Bryon, 2002) or have been based on very small samples (Soanes & Timmons, 2004).

In 1995 research was carried out with 104 young people with CF attending a major CF centre in the UK (Pownceby, 1995). The study consisted of interviews with young people with CF and the use of four standardised psychometric tests. The present study differs from this previous research in adopting a solely qualitative approach. Soanes and Timmons (2004) suggest that a much richer in depth picture of the attitudes of young people is needed in relation to transition. Although previous research has gone some way in providing this it has thus far failed to relate

this to wider aspects of young people's lives. By speaking to young people with CF about the transition to adulthood in general the present study hopes to generate not only rich and in depth information with regard to the transition to adult care but also an understanding of the way in which this relates to and interweaves with other aspects of their lives and in particular other areas of transition in their lives.

The final section of the review will focus on research that has examined the views and experiences of chronically ill/disabled young people during the transition to adulthood. This research will be linked back to the perspectives of chronic illness and disability, highlighted earlier in the review, where appropriate.

2.8 Research examining the views and experiences of chronically ill/disabled young people

This section will provide a review of qualitative research that has examined the subjective experience of young people living with CF and other chronic illnesses/disability. It will then review both quantitative and qualitative studies that have focused on specific aspects of living with chronic illness/disability for young people. This will provide a picture of what is currently known about the experiences of young people living with CF.

There has been very little research on the psychosocial impact and dynamics of CF during the transition to adulthood. Palmer and Boisen (2002) noted that most of the literature on psychosocial aspects of CF in young adulthood has tended to rely on psychological tests and quality of life measures and has formed conclusions based solely on these results. Such information is useful and important but they have argued that it needs to be expanded upon by providing qualitative information on the direct experiences and perceptions of people with CF, something the present study aims to do. They conducted a qualitative study with young people with CF in the US, focusing on the impact of the disease during the transition to adulthood. Their study yielded rich and in depth accounts however, their sample size was small, consisting of only seven participants.

From their exploratory study of young people with CF aged 20-26 years Palmer and Boisen (2002) reported a number of themes:

- Independence and normalisation – all participants had progressed or were in the process of progressing through the ‘normal’ transition to adulthood as defined by societal expectations. They had all achieved some level of normalcy and independence from their parents. Having CF had affected some of their choices but had not prevented them achieving their goals. They all reported an active, independent and normal social life with friendships, relationships and activities typical for young adults at this stage of life.

- **Stress** – treatments were identified as a source of stress as they created difficulties for the young people in fitting in.
- **Coping** – the participants displayed coping mechanisms and attitudes that minimised the negative aspects of having CF such as keeping things in perspective.
- **New responsibilities** – most of the participants felt they had taken responsibility for their own health care long before entering adulthood. This aspect of transition made them feel different from their peers.
- **Resiliency** – participants articulated a number of strengths and skills that assisted them in making the transition to adulthood. They expressed goals and hopes for the future, indicating hope and a positive outlook.

The study painted a very positive picture of young people living with CF and making a successful transition to adulthood with relatively few problems. However, the findings may not be representative of young people with CF in general as they are based on a very small sample consisting of only 7 participants.

Published after the present study started, Badlan (2006) conducted interviews with thirty-one young adults with CF in the UK, aged 17-39 years. She found participants had a strong desire to integrate into society and to be seen as normal. However, this was in conflict with some aspects of their recommended treatment schedule. Some participants expressed feelings of ambiguity in

determining whether they were normal or abnormal. Whilst their lives included many social norms such as jobs and busy social lives they also included some differences not considered normal such as a daily treatment regime. Badlan found that internal control and responsibility for self were important factors in dealing with CF. Some participants had experienced emotional difficulty in accepting the disease.

Tracy (1997) interviewed 10 adults with CF about their experiences of growing up with CF.

Three themes of memories were generated:

- Being different – participants recalled feeling different to their healthy peers.
- Don't call me terminal – participants were critical of the medical society's tendency to treat CF patients as statistics rather than individuals.
- Will power and faith – participants expressed their wish to focus on goals instead of suffering.

Christian and D'Auria (1997) interviewed 20 adolescents aged 12-18 years about their memories of growing up with CF. Reducing a sense of difference was the central phenomenon that described the adolescents' memories. This was achieved through the use of three protective strategies:

- Keeping secrets – the adolescents recalled using the strategy of concealing their CF to avoid the negative reactions of peers.
- Hiding visible differences such as taking medication.
- Discovering a new baseline – the adolescents recalled that as their cognitive abilities had matured they began to realise comparing themselves with healthy peers was the wrong standard for their lives. Differences due to having CF meant they had to discover a new baseline for their lives in order to reduce a sense of difference. The outstanding event that helped them to achieve this was meeting others with CF.

Gjendegal and Wabl (2003) conducted focus groups with adults with CF aged 23-42 years and parents of children with CF. They noted how participants repeatedly emphasised how important it was for them to lead a normal life even if the price they had to pay, in form of efforts was rather high. Leading a normal life in addition to carrying out their demanding treatment regime meant that participants had to rely on careful planning. In the presence of others they were reluctant to speak about their illness and tended to play down their problems for fear of being stigmatised or losing friends. Participants in this study also displayed a tendency to regard extraordinary activities, such as the need to adhere to a daily time consuming treatment regime, as normal. Strauss *et al.* (1984) described this phenomenon as a redefinition of normal.

Admi (1996) conducted a retrospective study of young people with CF aged 16-25 years and their family members. She identified four major categories as central in the lives of adolescents and young adults who have grown up with CF:

- Perceiving the self and centrality of the disease – participants' characterised early adolescence as a time of growing awareness about CF and this often led to the development of extreme positions. By late adolescence/early adulthood they had developed more mature views about their health condition such as flexible adherence to treatments as opposed to complete adherence or non-adherence. Participants were not preoccupied with thoughts of death and their overall orientation was towards continuity of life.
- Constructing the view of others' perceptions of people with CF – participants were aware that most people did not know about CF and those that did usually knew of the shortened life expectancy. They made a distinction between people who knew someone with CF and those that didn't with the latter being perceived as holding more misconceptions and stigmatising conceptions.
- Managing disease related information – three concepts of telling emerged these were: the choice of audience, the choice of situation and the choice of telling strategy. Managing potentially stigmatising information was found to be a complex and dynamic process. In any given situation a specific telling strategy was chosen according to the specific audience's behaviour and situational factors. As time went on the participants had developed the ability to identify the potential reaction of different people to disclosure.

- Managing medical regimes – as participants had grown up they had found ways to routinise and modify their regimes in order to maintain their health and reduce interference with their social life.

Admi concluded that the participants led vital and ambitious lives while continuing to plan their futures. They were fully aware of their disease but remained optimistic. Admi argued that CF was of little centrality and relevance to the participants' self-image, identity, everyday lives and future plans. The participants did not view themselves as deviant, sick or as victims. These findings are similar to those of Schur, Gamsu & Barley (1999) who conducted qualitative interviews with young people with diabetes. They noted how participants seemed to have developed identities for themselves, which were normal, valued and relatively independent of diabetes.

Contrary to this Watson, Shakespeare & Cunningham-Burley *et al.* (1999) conducted research with disabled children aged 11-16 years. They found that having an impairment did hold relevance for the identities of some of the young people they interviewed. They noted how the young people identified with the term disability in many different ways. Sometimes they saw themselves as the same as others with their impairment or as a wider group of disabled young people. Sometimes they saw disability as something which marked their difference from other children. Some disavowed the label for themselves whilst ascribing it to others.

When asked what disability meant to them the young people gave a variety of responses. Some children gave very specific and practical explanations of disability in terms of the way impairment impinged on their lives. For some being disabled meant encountering disabling barriers in the social world i.e. access problems and negative reactions of others. For others being disabled meant having a visible impairment. This definition meant that those with a hidden impairment could exclude themselves from the category of disabled. Schur *et al.* noted how the young people in their study engaged in stigma management to manage other people's reactions by hiding the visibility of their diabetes and seeking to maintain their identity as a well person.

Watson *et al.* noted that the accounts of young people in their research demonstrated that the term disability can have many different meanings. Thomas's (1999) social relational approach to disability as outlined in section 2.3 goes some way in integrating and explaining these different meanings. A social relational approach to disability acknowledges that having an impairment will directly cause some restriction of activity; such restrictions were highlighted in Watson *et al.*'s study. However, Thomas argued this in itself does not constitute disability; disability only comes into play when restrictions of activity are socially imposed. The young people's accounts also highlighted both socio-structural and psycho-emotional barriers that they had encountered which, Thomas referred to as barriers to doing and barriers to being.

People with chronic illnesses such as CF do not necessarily identify as disabled, perhaps because they do not have a visible impairment and are effectively able to pass as normal. However,

whilst people with CF will inevitably experience problems as a direct result of the condition this does not mean they will not experience disability in the form of socio-structural and psycho-emotional barriers. This was highlighted in Pownceby's (1995) study of 104 young people with CF. Asked what was the worst thing about having CF the most common response cited by almost a quarter of respondents was stigma and discrimination. The young people in Schur *et al*'s study hid their condition from others for fear of stigma even when they had no actual experience of stigma.

As discussed in section 2.3 there have been calls from disabled feminists for an approach to disability that can account for the experiences of the chronically ill as well as those with visible impairments who are more typically defined as disabled. Reeve (2004) has suggested that a social relational approach may be the way forward.

A thread that runs throughout much of the research described above is the desire of people with CF to lead a normal life and not be treated differently to their peers. In their report on how to improve health services for young people with CF Carpenter, Carpenter & Collins *et al.* (2004) also highlighted the need of the young person with CF to live as normal a life as possible. This they argued can be achieved through successful control of their CF.

The process of normalisation can take a number of different forms. The above studies conceptualise normalisation as a positive strategy/strategies that enable the young person with

CF to lead a fulfilling life. However, as noted in section 2.2 normalisation also has the potential to create serious problems and lead to a denial of the implications of illness (Thorne, 1993). For some a certain level of denial may be an adaptive strategy that enables them to live with hope. Others however, may take this to the extreme.

The studies reviewed above have identified a number of strategies used by people with CF in an attempt to lead a normal life. However, it is questionable whether these strategies have been explored in enough depth to reveal any potential negative consequences. For example, the participants in Christian and D'Auria's (1997) study used strategies such as keeping secrets and hiding visible differences to reduce a sense of difference. The potential negative comeback of using such strategies is not discussed. Pownceby (1995) found that only a small proportion of young people felt that CF took over their lives and a larger number took a middle ground position. The largest group stated that they ignored their CF to varying degrees and Pownceby noted that their comments suggested less conscientious attitudes towards treatment. However, no firm conclusions were made.

Thorne (1993) has argued that normalisation is a double edged sword and whilst it may be beneficial for a large number of young people with CF it should not be assumed that this will be the case for everyone. It would seem that for people living under the shadow of a life limiting illness, the desire to avoid thinking about it and to concentrate on the here and now seems to be a powerful means of coping (Small & Rhodes, 2000). It could be argued that future research

needs to take account of the potential negative impacts (if there are any) of trying to lead a normal life in spite of chronic illness, as well as the positive impacts.

The research reviewed thus far also reveals the various stressors and difficulties that young people with a chronic illness face such as dealing with a sense of difference, making decisions about disclosure and carrying out a daily time consuming treatment regime. Woodgate (1998) conducted interviews with adolescents who had a chronic illness. The adolescents described living with chronic illness as hard and felt they were confronted with obstacles on a daily basis. This was particularly so during unstable periods when their symptoms were most severe. Despite this during more stable times they described their lives as normal.

Woodgate identified four categories that emphasised the difficult nature of the chronic illness experience:

- It takes extra effort – participants felt managing a chronic illness required physical, mental and emotional effort.
- It's restricting – most had experienced restrictions due to the chronic illness such as participating in social activities.

- It's painful – participants spoke of painful symptoms as well as the pain and distress they experienced due to the effect of the illness on their daily lives.
- It's a whole bunch of worries – besides the everyday worries like friends and school they also had to worry about their health and the consequences of having a chronic illness.

This section will now review research that has focused on specific aspects of chronic illness/disability in adolescence and young adulthood.

2.8.1 Coping

The literature on how adolescents and young people cope with their chronic illness and the various stressors and difficulties it presents is scarce. It has already been noted how many employ various strategies in order to lead as normal a life as possible. Research on adolescents with chronic illness suggests that they use a variety of coping strategies (e.g. Ollson, Bond & Johnson *et al.*, 2003; Davidson, Penney & Muller *et al.*, 2004). Woodgate (1998) noted how the participants in her study used a number of strategies to deal with the difficulties of having a chronic illness and to develop and maintain a positive sense of self. These included making the best of things, talking to someone and not making the chronic illness their number one priority. Abbott *et al.* (2001) used a CF specific coping scale with adolescents and adults. They found that people with CF used a variety of coping strategies but the principle way of coping was

optimistic coping. This was followed by avoidance, hopefulness and the least used was distraction/emotional strategies.

Davidson *et al.* (2004) interviewed young people with diabetes and found that they had a variety of both problem-solving and emotion-based coping strategies that they used with varying degrees of success. Many of them had developed strategies to help them remember to do their care such as setting up routines. As noted in section 2.4.3, emotion-based coping is often considered to be maladaptive. However, the young people all reported that using strategies such as self-blame and guilt motivated them to do better. This supports Abbott's (2003) suggestion that to simply ask which coping strategies are adaptive/maladaptive now appears somewhat naïve. Researchers need to consider both the complexity and individuality of coping, especially for adolescents and young people where the literature is so severely lacking.

2.8.2 Experiences of school

School is often a place where chronically ill/disabled young people experience much difficulty. Pupils with chronic illness straddle policy boundaries between education and health with no single policy document to identify their needs and give guidance on supporting them (Lightfoot, Mukherjee & Sloper, 2001). In a study of young people with special healthcare needs attending mainstream schools, Lightfoot *et al.* (2001) found wide variations in the extent to which their support needs were being met.

Whilst many young people are able to actively manage the effects of their condition in school a number of difficulties may arise due to: the implications of absence; exclusion from school life; teacher's reactions to the illness; difficulties with peer relations and the need to carry out treatments during school hours (Lightfoot, Wright & Sloper, 1999). D'Auria, Christian & Henderson *et al.* (2000) found that having CF interfered with their participants' ability to participate in school and many reported feeling out of place upon their return from a brief or prolonged school absence. Some researchers have also found bullying to be a significant problem for chronically ill/disabled young people in school (e.g. Watson *et al.*, 1999; Connors & Stalker, 2003).

2.8.3 Attainment of adult status

In spite of such difficulties studies of adolescents and adults with CF tend to emphasise that this group has good educational and work records when compared with the general healthy population Tyrell, (2001). In a UK survey of people with CF over the age of 16 years Walters, Britton & Hodson (1993) found that 55% of respondents were employed with half of those unemployed citing ill health as the reason. However, revealing they had CF at interviews was found to have reduced the chance of being employed for those with mild-moderate disease. Respondents had been less successful than the general population in achieving O' Level's or equivalent but had been more successful in achieving A' Levels or higher qualifications.

Overall, 56% of men and 48% of women lived with their parents. A total of 34% were married or cohabiting compared with 61% of the general population at that time. The study identified areas where the CF population may need additional support i.e. in achieving independent living but it also revealed that many are living productive and fulfilling lives into adulthood.

Burker, Sedway & Carone *et al.* (2005) conducted a US study of 183 adults with CF. The vast majority of respondents had at least a high school education and almost half were employed at that time. This stands in sharp contrast with Clark and Hirst's (1989) UK study of the attainment of adult status for physically impaired people. They concluded that a sizeable minority of participants were unlikely to achieve the basic goals of adulthood, due to major inadequacies in support processes for disabled people who want to work and live independently. Hendey and Pascall (2002) also reported that disabled young adults found it difficult to achieve adult status.

2.8.4 Experiences of healthcare

Previous studies have found that many young people with CF have good relationships with their health care team (e.g. Carpenter *et al.*, 2004). However, other studies (e.g. Farrant & Watson, 2004) have reported that many young people with chronic illness are dissatisfied with the health care they receive. A study by Beresford and Sloper (2003) highlighted that young people want a person-centered approach from health care professionals rather than a condition-centered approach, which isolates them.

Such studies have highlighted the many discrepancies between individual experiences of clinic, hospital and medical treatment (Carpenter *et al.*, 2004). An issue of concern highlighted in a number of studies is that young people feel they have unmet information needs. They would like more information on and discussion about a wider range of topics including: the impact of having a chronic illness on day to day life; advice about jobs and careers, advice on how to explain CF to others; mental health issues; emotional health issues and other social issues (Carpenter *et al.*, 2004; Dovey-Pearce, Hurrell & May *et al.*, 2005; Farrant & Watson, 2004; Beresford & Sloper, 2003).

Participants' in Beresford and Sloper's study stressed that having information on these topics is as important as knowing about the condition and its management. However, they felt that health care professionals were not aware of or interested in the wider implications of living with a chronic illness and this in turn made them reluctant to raise these sorts of issues. Young people may also find it difficult to discuss treatment difficulties with their doctor. Pownceby (1995) found that almost a quarter of participants felt their doctor did not understand the wider implications of treatment on their lives. A similar number felt that their doctor's approach was so rigid they were unable to discuss treatment difficulties. Disability theorists have expressed much concern over the role of health professionals in the lives of disabled people, particularly in the lives of children and young people (see section 2.3). Research seems to suggest that some young people do not feel their health care needs are being met on a more holistic level and they are unable to discuss this with their health care team.

2.8.5 Treatment adherence

As with studies of adults, studies of adolescents and young adults reveal that complete adherence is rare. In a large scale study of chronically ill adolescents in Finland, Kyngas (2000) found that 23% of participants placed themselves in the category of total adherence, 60% in the category of satisfactory adherence and the final 19% in the category of poor adherence. In Pownceby's (1995) UK study of young people with CF only 15% rated themselves as totally adherent.

A number of factors have been found to influence adherence in adolescence including medical, cognitive, emotional, motivational, family, peers, relations with health care professionals and patient education (Kyngas, Kroll & Duffy, 2000). In her study Kyngas (2000) found adherence was promoted by a strong sense of normality, a positive attitude towards the disease and treatment, energy and will-power, experience of results, support from parents, nurses, doctors, and a feeling that the disease was not a threat to social well-being. Support, in particular, has been identified as a crucial factor (Kyngas & Rissanen, 2001; Gillibrand & Stevenson, 2006). Foster, Eiser & Oades *et al.* (2001) identified three types of non-adherence for young people with CF and their families:

- Unintentional – such as forgetting to take tablets

- Intentional – this was particularly common in older adolescents and included not being able to be bothered to carry out treatment
- Imposed – this was non-adherence due to external forces i.e. practical restraints such as time pressures or perceived social pressures such as not wanting to be different from peers.

Studies of adults with CF have shown adherence to vary with different aspects of the treatment regime (see section 2.4.3). The same has also been found in studies of young people with CF (e.g. Pownceby, 1995; Modi, Lim & Yu *et al.*, 2006). Pownceby found over 50% of participants rated themselves as totally compliant with vitamin supplements and oral antibiotics whilst fewer than 50% rated themselves totally compliant for physiotherapy and pancreatic enzymes.

Pownceby noted that these results were somewhat surprising as the benefits/disadvantages of non-adherence are more immediately felt with enzymes than vitamins. As noted in section 2.4.3, Abbott *et al.* (1994) found that for adults with CF the lowest adherence rates occurred with physiotherapy and vitamin supplements as there was no immediate risk or discomfort associated with non-adherence.

Pownceby found the lowest rate of total adherence occurred with physiotherapy. Participants cited a number of reasons for this including: can't be bothered; not enough time; interference with social life; feeling well without it and no perceived immediate benefit from it. Williams, Mukhopadhyay & Dowell *et al.* (2007) also found that children and young people with CF and their parents felt physiotherapy was particularly problematic. Participants frequently described

physiotherapy as restrictive, threatening to identity and boring. This gave rise to feelings of unfairness, inequality, difference and social stigma. Williams *et al.* noted how motivation to overcome these problems might be undermined by perceptions of ineffectiveness.

Adolescence is commonly seen as a time when young people will rebel and refuse to do their treatments (Fitzgerald, 2001). However, Pownceby's study included people between the ages of 13 and 24 years. She found no association between age and adherence and argued that this belies the commonly held assumption that non-adherence is primarily a problem of adolescence. In her qualitative study of young people with CF, Badlan (2006) noted that most of the participants believed they were in control of their own health care and had made careful considered decisions about their levels of adherence. She argued that the central concern of health care professionals should not be to maximise adherence but to support the making of informed decisions about broader lifestyles and health behaviours.

2.8.6 Social support

Social support, that is emotional, instrumental and informational support is regarded as a crucial factor for young people with chronic illness (Kyngas, 2004). Research has demonstrated that social support can promote coping with chronic illness (e.g. Graetz, Shute & Sawyer, 2000) and treatment adherence (e.g. Kyngas & Rissanen, 2001). Kyngas and Rissanen found the most important members of the young person's support network to be family members, friends and

health care professionals. Participants in Pownceby's study were asked who they would turn to for support when worried about their CF. The majority (58%) said they would talk to a family member, just under 35% said they would talk to a friend and just under 15% said they would talk to a health care professional. Kyngas (2004) also found that chat rooms were an extremely important part of an adolescent's support network as they allowed them to communicate anonymously, freely sharing their emotions and issues.

Graetz *et al.* (2000) interviewed adolescents with CF about their perceived supportive and non-supportive behaviours of family and friends. Families provided them with tangible support such as help with treatments but also engaged in non-supportive behaviours such as nagging. Friends were seen to provide more companionship but could also engage in non-supportive behaviours such as drawing attention to the illness in public.

Kyngas (2004) also found that the support of families could have a positive or negative impact for adolescents with a chronic illness, depending on the type of communication. When parents engaged in open discussion this enabled the adolescents to share almost all of their issues and emotions with them. This in turn helped them to cope with their illness. When discussion focused on questions of how well the adolescent had taken care of themselves the adolescents felt irritated and that their parents were not interested in them as their children.

The adolescents also identified their peers as an important part of their support network. They particularly valued the support of others with a chronic illness. As reviewed earlier, the adolescents with CF in Christian and D'Auria's study were able to discover a new baseline for their own lives by meeting others with CF. However, due to the risk of cross infection people with CF are strongly discouraged from mixing with others with the condition. Pownceby found that 70% of respondents did not have any friends with CF. Carpenter *et al.* (2004) found that young people with CF would like to chat with others who have the condition and were frustrated by the lack of contact.

Having a chronic illness may make peer relationships more difficult and Carpenter *et al.* found that many young people occasionally felt isolated from their friends because of their CF.

Pownceby found that the majority of participants had no difficulty in making friends. However, one third stated that having CF made them feel different from their friends. This group were also significantly more likely to have difficulty in disclosing the condition to friends for fear of not being socially accepted, exciting sympathy or having their identity reduced simply to the fact of their CF. A further 14% expressed difficulty in disclosing to the opposite sex for fear of rejection.

Quinn (1996) conducted a study of young people with CF and found that 40% would avoid telling people about their condition as far as possible. A further 40% said they would not discuss it at all. Quinn noted that for some, distancing was a common reaction that enabled them to cope with their illness. Others however, took this to the extreme and would not tell anyone they had

CF. Peers are only able to provide disease specific social support if they know about their friends chronic illness. As noted earlier, Admi's study highlighted that managing potentially stigmatising information is a complex and dynamic process for young people. Such findings indicate that some may need advice on disclosing their condition in positive ways. Thus far little attention has been devoted to how and when young people disclose their chronic illness to friends (La Greca, Bearman & Moore, 2002).

2.9 Summary and rationale for the present study

Researchers from a wide range of disciplines have addressed the various issues around living with chronic illness/disability. However, much of this research has been with adults who have enjoyed a long span of good health before becoming ill or injured. Therefore the present study focused solely on the experiences of young people with CF – a condition present from birth.

The three main disciplines reviewed above, sociology, disability studies and psychology, have all been criticised for failing to take account of the whole experience of living with chronic illness/disability. It has been argued that a social relational view of disability as advocated by Thomas (1999) could go some way in resolving these criticisms and this approach can be linked back to work in all three disciplines. A social relational approach accounts for the problems that people experience as a direct result of their impairment and the wider implications of this – something that sociologists have focused on. It can also account for the socio-structural barriers

encountered by those with impairments, which have been a major focus of disability theorists. Finally this approach also addresses the psycho-emotional dimension of disability and thus the psychological impact of having an impairment and the resultant disablism that may occur.

It could be argued that such an approach has the potential to bridge some of the gaps that currently exist between different disciplines. Forming allegiances between disciplines could give people with chronic illness the opportunity to articulate not just their medical needs but also their social needs, whether they choose to identify as disabled or not. The present study acknowledged that having CF would have a direct impact on the lives of participants but it did not assume that participants would have experienced disability in the form of socially imposed disadvantage. However, by speaking to young people themselves about their experiences of the transition to adulthood I hoped to identify from their accounts whether they had experienced disability and if so how.

It could be argued that researchers themselves now need to broaden their approaches within the field of chronic illness. The present study has reviewed previous research on chronic illness and disability from a range of disciplines. In doing so I endeavored to strike a balance between the often opposing camps of medical sociologists, disability theorists and psychologists. Such an approach means that data can be considered within a range of disciplines in an attempt to begin to broaden and enhance what is currently known about the experience of living with CF and chronic illness more generally for young people.

There is much literature which suggests that being chronically ill/disabled is likely to make adolescence more difficult and present additional challenges in the transition to adulthood. However, there is very little research that has addressed the transition to adulthood for those with a chronic illness and even less that has focused on young people with CF, for whom the transition to adulthood is a major milestone only recently actualised. Currently very little is known about this stage of life for those with CF. Therefore, research is needed that focuses on this specific stage of life, as the present study does.

The transition to adult care for young people with chronic illness has received much attention in recent years. This transition is regarded as an important milestone for those with chronic illness and one that can impact upon many areas of a young person's life. Despite this most of the literature available is in the form of policy documents. Of the little research that has been conducted much has been quantitative or has relied on the accounts of parents or health professionals. By inviting young people with CF to speak freely about their experiences of the transition process the present study aimed to provide a more in depth account than has so far been achieved.

Only a few studies have focused qualitatively on how young people with CF experience their lives. The present study differs from previous research in this area in a number of ways. Unlike previous research (e.g. Gjendegal & Wabl, 2003; Admi, 1996) the present study focuses solely on the perspectives of young people with CF and does not rely on retrospective accounts of growing up with CF (e.g. Christian & D'Auria, 1997; Tracy, 1997). Previous studies have

recruited participants with a much wider age range (e.g. Badlan, 2006; Gjendegal & Wabl, 2003) than the present study, which focuses on a specific stage of life.

The active role of young people in the experience of illness has thus far been largely neglected within all the disciplines reviewed above. Such research is needed to enable the delivery of services that are sensitive to the needs and priorities of young people with illnesses, particularly chronic illnesses such as CF where young people often rely heavily on services. The present study aimed to fill a gap in current research by providing insight into the subjective worlds of young people with CF currently undergoing the transition to adulthood. This is something research has so far failed to do.

CHAPTER 3

METHODOLOGY

This chapter will provide an overview of the methodological approach adopted for the present study. It will present the philosophical background of the study and thus explain why the grounded theory methodology was chosen. It will then focus on the grounded theory methodology and provide a review of its background, strategies, data collection methods, ethical implications and finally how rigour can be ensured in a grounded theory study.

3.1 Philosophical background

The approach to this research was very much informed by my own background in childhood studies and in particular the sociology of childhood and youth and emerging paradigm of disability studies. Recent years have seen an increasing interest in listening to the experiences of children and young people, in line with the establishment of a new paradigm for the study of childhood and youth (France, Bendelow & Williams, 2000). It was felt to truly provide insight into the subjective worlds of participants a qualitative approach was necessary.

Research on youth and youth related issues has recently become a major growth area for social researchers. However, such research often focuses on anxieties about a dangerous/problematic youth (France, 2004). Traditionally youth has been understood as a universal experience with a linear transition from childhood to adulthood and this dominant discourse has influenced how policy is shaped. In much legislation youth does not exist and this is reflected in The Children Act 1989 where all those under the age of eighteen are considered to be children (France, 2004).

Historically researchers have marginalised the voice of young people and much social research has been focused on rather than with them. However, France (2004) argued that as a result of three major developments in recent years a new orthodoxy is emerging that encourages us to listen to the voices of young people and put their voices at the centre of the research process, these are:

- A growing interest in childhood studies and the contribution children can make to our understanding of childhood
- A growth in legislation over the last 20 years that supports and values the voice of children and young people

- Since the 1997 election of New Labour there has been a growing interest in listening to children and young people and policy development has opened doors towards an approach that wants to hear what children and young people have to say.

By acknowledging that they are social actors, research with young people can move beyond merely describing what they see and experience to eliciting their meanings and interpretations of what it is to be a young person in the society in which, they live (Mayall, 1999). In order to do so research with young people needs to be interactive, participatory and reflexive and requires an approach that puts young people at the centre of focus, such as grounded theory (France *et al.*, 2000).

A number of methodologies could have been adopted that are consistent with newer approaches to children and young people such as grounded theory, phenomenology or narrative approaches. Each of these approaches would have acknowledged young people as social actors and provided a means to eliciting their own meanings and interpretations. However, after careful consideration the grounded theory methodology was adopted for a number of reasons, these are:

- Grounded theory provides systematic, inductive guidelines for collecting and analysing data and as a novice researcher it was important to have this structure.

- **Constructivist grounded theory pays particular attention to addressing the power imbalance between the researcher and researched. This is of particular significance when doing research with young people who have typically been viewed as subordinate to adults.**
- **Unlike other approaches, such as phenomenology, grounded theory research becomes increasingly focused as the research progresses thus allowing the researcher to focus on the issues of greatest importance to participants. Therefore, I felt that using this approach would give the young people themselves greater opportunity to shape the research agenda.**
- **Narrative approaches focus on people's life stories and in particular the ways in which they have been disrupted for example, by the onset of chronic illness. Due to the age of the young people that would be participating in the present study I was concerned that the level of disruption in their lives and to their life stories thus far as a consequence of their condition would be very minimal. Therefore I decided a narrative approach would not be the most appropriate.**
- **Both phenomenological and narrative approaches would have generated an understanding of the phenomenon under study. However, the aim of a grounded theory study is to try and develop a theory. I felt this would make the greatest contribution to the field as currently very little is known about the transition to adulthood for young people with CF.**

- Adopting the grounded theory methodology ensures that theory is not the driving force to conceptualising the lives of young people; rather it can emerge from the data under investigation (France *et al.*, 2000).

There has been a shift in thought within social sciences whereby children and young people are now seen as being actively involved in the construction of their own social lives, the lives of those around them and of the societies in which they live (James & Prout, 1997). Despite this it is generally felt that the active role of children and young people in the experience of illness has not been considered (Sartain, Clarke & Heyman, 2000). There is a general expectation that health care should seek to deliver services that are sensitive to the needs and priorities of its users. However, few interpretive studies have been conducted where children and young people are considered active users of services rather than passive recipients of the health care system. Rather it is often the case that an adult view is imposed as proxy for the child or young person's perspective (Sartain *et al.*, 2000). It is suggested that for children and young people with chronic illness this raises particularly pertinent issues and researchers interested in the study of illness are now calling for more research with children and young people that is guided by the qualitative paradigm (Sartain *et al.*, 2000).

In recent decades sociologists have begun to study experiences of illness and in particular chronic illness. Such research typically focuses directly and explicitly on the subjective experience of living with and in spite of illness (Gerhardt, 1990); however, such research has tended to focus on adults. Several observers have noted that qualitative research methods are

necessary to explore the subtle and personal meanings that inhere to living with chronic illness (Gerhardt, 1990). It is further noted that a fundamentally more concrete image emerges of what it is like from the point of view of the person concerned, to live with a chronic illness with the use of qualitative methods, than would be achieved using quantitative methods such as a standardised questionnaire (Flick, Kardorff & Steinke, 2004).

However, there is increasing division between medical sociologists and disability theorists and the two camps tend to provide separate and competing accounts rather than a joint account of illness and disability (Barnes & Mercer, 1996). As outlined in section 2.2, medical sociologists have typically focused on the meaning of illness within its context (Williams, 1996) and the problems chronic illness and disability create for individuals (Barnes & Mercer, 1996).

Such an approach is criticised by disability theorists for being one-dimensional and creating a category of negative consequences and meanings that gives too much weight to subjective meaning and too little attention to wider structural forces (Barnes & Mercer, 1996). As discussed in section 2.3, the sociological approach to chronic illness and disability has in recent years been severely challenged by a socio-political perspective that has advanced the social model of disability. In response sociologists have criticised disability theorists for ignoring the complex issues in the experience of chronic illness and impairment and have argued there is a danger of generating an over socialised view of disability (Bury, 1996).

The social model of disability has thus far paid little attention to disabled children and young people and few studies have focused specifically on children and young people's perceptions and experiences of impairment and disability (Connors & Stalker, 2007). Connors and Stalker suggested that a social relational model of disability, outlined in section 2.3, provides a useful framework for understanding children and young people's experiences of impairment and disability as it relates directly to people's lived experience. Such an approach acknowledges that people apply their own meanings to the experience of impairment and thus recognises that an adult view of impairment and disability should not be used as proxy for the views of children and young people. This approach does not assume that all disadvantage or restriction experienced by people with impairments constitutes disability. Disability only comes into play when such disadvantage or restrictions are socially imposed (Thomas, 2001).

A dilemma for researchers who try to convey the experience of impairment and disability is the significance that should be allocated to people's subjective experiences (Barnes & Mercer, 1997). Drawing upon the basic principles of a social relational approach the present study adopted an inside out approach, that is emphasis was placed on the experiences and subjective realities of participants. In doing so I recognised that in having CF participants could therefore be defined as living with impairment and as such experiencing impairment effects. However, I did not assume participants had necessarily experienced disability, defined by Thomas (1999) as socially imposed disadvantage or restriction of activity.

By researching the experiences of young people with CF making the transition to adulthood I hoped to identify whether they had experienced disability and if so how. In doing so I endeavoured to strike a balance somewhere between the two opposing camps of medical sociologists and disability theorists by gaining insight into the personal experiences of transition to adulthood for this group of young people as well as identifying what if any socially imposed barriers they feel they have to overcome in making the transition. As such I felt an interpretive approach was necessary.

3.2 Grounded Theory Methodology

Grounded theory is an interpretive research methodology that consists of systematic inductive guidelines for collecting and analysing data (Charmaz, 2000). Charmaz (1990) postulated that the grounded theory method provides a set of useful research strategies for studying the experience of chronic illness. She noted that people with chronic illness like most people experience their constructions as reality. Their constructions reflect their understanding of their experiences and friends and family will often support their constructions even when they challenge or contradict those of medical professionals.

Charmaz has suggested that grounded theory analyses can provide physicians with alternative understandings of patients' beliefs and actions and they may then use these to improve communications with patients and to act on problems, which patients define. Grounded theory is a methodology that seeks to construct theory about issues of importance in people's lives (Mills,

Bonner & Francis, 2006¹). Schrieber & Stern (2001) considered it to be the method of choice when researchers want to learn how people manage their lives in the context of existing or potential health challenges.

The methodology was initially developed by Glaser and Strauss (1967) in the 1960's who stated the objective of grounded theory is to develop a theory from the data, which, is encompassed in a core category and related categories and concepts. They further stated the importance of theory being grounded in the data, not predicted by any theoretical perspective. In order to achieve this, the researcher must be immersed in the data, which requires them to take an emic approach to collecting and analysing data (McCann & Clark, 2003¹). An emic approach entails having empathetic understanding of the insider's point of view and exploring the meanings they give to their ideas, feelings, experiences and perceptions. The researcher then takes an etic approach later on in the research process. This entails taking an outsider perspective in order to interpret meanings of participants and provide explanations for events and actions (McCann & Clark, 2003¹).

Glaser and Strauss (1967) noted that the grounded theory methodology might be used to produce two types of theory. A substantive theory is the most common and concentrates on specific social processes and is developed from a narrower empirical area of study. A formal theory is more general and deals with a conceptual area of enquiry. McCallin (2003) also stressed that in small-scale research projects it is acceptable to use the grounded theory methodology to describe and explain some underlying social processes shaping interaction and behaviour.

The grounded theory methodology is derived from the theoretical framework of symbolic interaction (Norton, 1999). This branch of interpretivism places emphasis on eliciting and understanding the way meaning is derived in social situations (McCann & Clark, 2003¹). Symbolic interactionism assumes that both the self and social reality are constructed through interaction, and as such relies on language and communication. It addresses how people create, enact and change meanings and actions and therefore assumes that people can and do think about their actions (Charmaz, 2000).

It is a common criticism that symbolic interactionism does not deal with larger questions concerning the shape of society (Annells, 1996) and as such fails to deal with macro level social processes, social structures and power dynamics (Dennis & Martin, 2005). In response to this criticism the approach to the present research differs from traditional symbolic interactionism and hence grounded theory as it was initially proposed. The starting point of the research was to study the subjective experiences of participants and the ways in which their experiences were constructed through interaction. However, in addition to this an awareness of the disability studies literature enabled me to be aware of larger social forces that may be at work and hence, address any macro level social processes, social structures and power dynamics as identified by the young people themselves.

Variations of grounded theory exist that reflect different epistemological underpinnings. Classic grounded theory as initially proposed by Glaser and Strauss (1967) is guided by critical realist ontology and is located within the positivist paradigm (McCann & Clark, 2003²). Since their

original publication Glaser and Strauss with his co-author Corbin have moved the methodology in conflicting directions. There is a vast amount of literature addressing the differences between the two approaches (e.g. Walter and Myrick, 2006; Duchscher & Morgan, 2004; Heath & Cowley, 2004; Melia, 1996).

Glaser's position (1978; 1998) remained closer to the positivist paradigm with assumptions of an objective external reality, neutral unbiased observer and objectivist rendering of the data.

Strauss and Corbin's works (1990; 1998) assumed an objective external reality, unbiased data collection, a set of technical procedures and espoused verification. However, their work moved into the post positivist paradigm as they also proposed giving a voice to participants. Charmaz (2000) firmly stated that their approach like Glaser's remained imbued within positivism with its objectivist underpinnings. However, some authors have argued that their work represents a shift towards the constructivist paradigm (e.g. McCann & Clark, 2003³).

Charmaz (2000; 2002; 2006) postulated that grounded theory strategies need not be rigid or prescriptive and that the power of the methodology lies in its techniques for understanding empirical worlds. She argued that grounded theorists could reclaim the methodology from its positivist underpinnings to form a revised more open ended practice. Charmaz added another vision for future qualitative research, one that has been adopted for this research study, that is constructivist grounded theory. This approach builds on the symbolic interactionist theoretical perspective with constructivist methods (Charmaz, 2002). The constructivist paradigm is opposed to positivism and is underpinned by a relativist ontology and subjectivist epistemology

(Lincoln & Guba, 2000), thereby recognising that researchers do not discover knowledge they construct it (Schwandt, 2000).

Constructivist grounded theory assumes that people create and maintain meaningful worlds and places emphasis on meaning without assuming the existence of a unidimensional external reality (Charmaz, 2000). It aims to provide an interpreted portrayal of the studied world not an exact picture (Charmaz, 2002). Constructivist grounded theorists need to be aware of their preconceptions and grapple with how they affect the research process (Charmaz, 2006). Mills, Bonner & Francis (2006²) noted how this approach requires a rethink of the traditional role of the grounded theorist. Grounded theory has traditionally been seen as silently authored with researchers seen as the distant expert. The constructivist approach repositions the researcher as author of the reconstruction of experience and meaning. It rejects the traditional role of the researcher as objective and requires a position of mutuality between researcher and participant. This in turn requires a sense of reciprocity.

Charmaz (2000) stressed that by recognising the interactive nature of data collection and analysis, the constructivist approach resolves recent criticisms of the method. Critics of the methodology have suggested that fracturing the data leads to separation of experience from the experiencing subject, meaning from the story and view from the viewers. However, the constructivist approach furthers knowledge of subjective experience and expands representations without remaining external or accepting objectivist assumptions (Charmaz, 2000). A further hazard of such an inductive method is over emphasis on the individual (Charmaz, 2000). This

can be addressed through consideration of macro influences on participants as well as micro influences, something the present study has done.

3.3 Strategies of grounded theory

Several permutations of grounded theory have evolved but they all require the researcher to address a set of common characteristics inherent within the methodology (Mills *et al.*, 2006¹). McCann and Clark (2003¹) identified 7 key characteristics: theoretical sensitivity; theoretical sampling; constant comparative analysis; coding and categorising data; theoretical memos; using literature as a source of data and integration of theory.

3.3.1 Theoretical Sensitivity

A researcher using grounded theory will already possess a set of sensitising concepts through their own disciplinary assumptions and theoretical perspective. These concepts can inform empirical enquiry and spark development of more refined concepts, negotiations and definitions of situations (Charmaz, 2002). They can also draw attention to the important features of social interactions and provide guidelines for the researcher (Bowen, 2006). Background assumptions can alert the researcher to look for certain processes and provide initial ideas to pursue.

However, Charmaz (2006) noted that it is important that sensitising concepts are used to develop rather than limit ideas. They should provide merely a point of departure for the researcher and

should never be used to force preconceived ideas and theories onto the data. Rather the researcher should pursue the topics that respondents define as important.

There is much confusion about the role of literature in providing theoretical sensitivity prior to data collection. McCann and Clark (2003¹) suggested that theoretical sensitivity can be gained from a preliminary literature review as long as researchers do not use the literature to impose existing frameworks. However, Glaser (1992) was of the opinion that researchers should not review any of the literature in the substantive area under study until theory becomes emergent due to a risk of biased interpretation of data. He further added that it is vital to be reading from the outset but in unrelated fields. However, this can create tension for novice researchers such as myself. This is especially difficult in doctoral research such as the present study where a detailed research proposal must be drawn up that justifies the need for the research to be conducted. Heath (2006) suggested that in such cases researchers could conduct a preliminary literature review but limit reading to abstracts. Thus, they can confirm the need for the study but avoid potential distortions stemming from detailed familiarity with the literature.

3.3.2 Theoretical Sampling

Theoretical sampling is driven by emerging theory and is therefore to be distinguished from initial sampling. Researchers begin with a purposeful sample, selecting participants who have a knowledge and experience of the phenomena under study (Milliken & Schrieber, 2001). As

initial data is collected and analysed the researcher makes decisions about the participant sample based on emerging theory and this is known as theoretical sampling (Glaser, 1978). Theoretical sampling is the process of identifying emerging categories, checking them, filling them out and where necessary returning to the field to extend them (Charmaz, 2000). The researcher will then collect pertinent data to elaborate and refine categories in the emerging theory. They will develop the properties of categories until no new properties emerge (Charmaz, 2006). Theoretical sampling will continue until theoretical saturation is achieved. Saturation has occurred when no new data is emerging relevant to the categories, categories have conceptual density and all variations within categories can be explained (McCann & Clark, 2003¹).

3.3.3 Constant Comparative Analysis

In grounded theory research data collection and analysis take place simultaneously and this is considered the principle approach to data analysis in the development of a grounded theory (McCann & Clark, 2003¹). Coding and constant comparative analysis yield the conceptual relationships between categories and their properties (Glaser, 1992). Researchers begin by comparing different people and their views, situations, actions, accounts and experiences. They then compare incident-to-incident, data with categories and categories with other categories (Charmaz, 2000). It is through such comparisons that the properties of a category are defined (Glaser, 1992).

3.3.4 Coding and Categorising Data

Coding initiates the process of theory development (McCann & Clark, 2003¹) and in grounded theory coding strategies are not meant to be used in a distinct and linear process (Heath & Cowley, 2004). Glaser and Strauss (1967) originally described 2 levels of coding. Strauss and Corbin (1990; 1998) however, have explicated 3 coding levels in their work. They provided more complex and detailed guidelines for coding including the use of a coding paradigm that encourages the researcher to focus on specific aspects of a phenomenon. Glaser (1992) has strongly criticised their approach to coding believing that it forces full conceptual description rather than articulating emergent theory. He has continued to advocate the use of two levels of coding (Glaser 1978; 1992; 2004).

Kelle (2005) advocates the approach of Strauss and Corbin (1990; 1998) for novice researchers who want clear advice on how to structure data material. Mills *et al.*, (2006¹) have supported the introduction of the paradigm model by Strauss and Corbin. They believed it provides a tool for reconstructing a grounded theory that is dense and significantly analytic as well as representative of both structure and process. By emphasising the importance of identifying structure as well as contextual, symbolic and interactional influences Strauss and Corbin highlighted the need to take account of both micro and macro influences (McCann & Clark, 2003³). In response to Glaser's (1992) criticisms Strauss and Corbin (1998) became more emphatic in their argument. They stressed that their guidelines should be used with a degree of flexibility and creativity and that researchers could pick and choose which, techniques to use.

The three levels of coding explicated by Strauss and Corbin (1990; 1998) are open, axial and selective. In open coding concepts are identified and their properties and dimensions are discovered in the data. The text is opened up to expose thoughts, ideas and meanings. Data is broken down into discrete parts and examined and compared for similarities and differences. This is achieved with line-by-line coding, where each line of written data is coded. This forces the researcher to concentrate on and become immersed in the data and thus avoid undue influence by any preconceived beliefs (Charmaz, 2006). The researcher can use two types of codes; in vivo codes or sociological constructs. In vivo codes directly relate to the language of the data and help avoid situations where the researcher may impose preconceived opinions on codes (McCann & Clark, 2003¹).

Eventually concepts can be grouped together into categories and thus reduce the number of units. A category will stand for a particular phenomenon and be able to depict a problem, issue, concern or matter that is important to those being studied. Once a category has been identified it can be developed in terms of its properties and dimensions. A category is derived by comparing data from each case and so should in a general sense, have relevance for and be applicable to all cases in the study.

Axial coding begins the process of reassembling data. It is the process of relating categories to subcategories through the use of a coding paradigm. A subcategory is also a category but does not stand for a particular phenomenon. Subcategories answer questions about the phenomenon

such as when, where, why, how and with what consequences? This in turn gives concepts greater explanatory power and enables the researcher to relate structure with process.

Structure sets the stage and creates the circumstances in which, problems, issues, happenings or events arise or are situated. Process is the actions/interactions over time of a person, organisation or community in response to certain problems or issues. The paradigm is an analytic tool used to help organise data and integrate structure with process. It has three basic components:

- Conditions are sets of events or happenings that create the situations, issues and problems pertaining to a phenomenon and to a certain extent can explain why and how a person or group responds in certain ways. Conditions may arise out of time, place, culture, rules, beliefs, economics or power as well as from social worlds, organisations and institutions.
- Actions/interactions are the strategic or routine responses made by individuals or groups to issues, problems, happenings or events that arise under those conditions.
- Consequences are represented by questions as to what happens as a result of those actions/interactions or the failure of a person or group to respond to situations.

Consideration of these components enables the analyst to discover the ways in which categories relate to each other.

Selective coding is the process of integrating and refining theory. The first step is to decide on a central/core category that represents the main theme of the research. The central category has analytic power and the ability to pull all the categories together. Strauss (1987) provided a list of criteria that can be applied to a category to determine if it qualifies as the central category:

- It must be central – all other major categories can be related to it
- It must appear frequently in the data
- It should be sufficiently abstract that it can be used to do research in other substantive areas
- It is able to account for considerable variation within categories.

Once the central category is identified all other major categories are related to it through explanatory statements of relationships.

Coding is cyclical, shifting from open to axial then to selective and at anytime the researcher could be simultaneously coding at several levels (McCann & Clark, 2003¹). Throughout the coding process researchers use the constant comparative method to establish analytic distinction and make comparisons at each level of analytic work (Charmaz, 2006).

3.3.5 Theoretical Memos

Memos are the pivotal intermediate step between data collection and writing the first draft (Charmaz, 2006). They are the notes that researchers make throughout the research process to record and explicate theory as it is developed and they reflect the researcher's internal dialogue with data at a point in time (McCann & Clark, 2003¹). Memos are a crucial method in grounded theory as they prompt the researcher to analyse data and code early in the research and consequently can help to crystallise questions and directions for the researcher to pursue (Charmaz, 2006). Memos are written in parallel to data analysis (Glaser, 2004) and are done so spontaneously. Writing memos enables the researcher to raise codes to conceptual categories as they contain narrative statements that: define categories; explicate the properties of categories; specify the conditions under which a category arises, is maintained and changes; describe the consequences of a category and show how a category relates to other categories (Charmaz, 2006).

3.3.6 Literature as a source of data

Despite confusion about the role of literature prior to data collection there is a general consensus that the main literature review should be delayed until theory begins to emerge. This avoids imposing predetermined understanding and existing frameworks on the investigation (Heath, 2006). This main literature review links existent research and theory with concepts, constructs and properties of the emerging theory. The literature illuminates, supports or extends the proposed theory and is interwoven with empirical data (Hutchinson, 1993).

3.3.7 Integration of Theory

McCann and Clark (2003¹) noted that throughout the process of theory generation there is interaction with the data and the use of memos aid the researcher to conceptualise the theory. It is not until all major categories are finally integrated that research findings can take the form of theory and findings should be presented as a set of interrelated concepts rather than just a list of themes (Strauss & Corbin, 1998). Glaser (1978) identified 3 key strategies to develop and add density to emergent theory: category reduction, selective sampling of the literature and selective sampling of data.

3.4 Data collection

Qualitative interviewing is particularly closely related to the approach of interpretive sociology (Hopf, 2004). Exploratory semi structured and unstructured interviews tend to be the primary data collection method in grounded theory research (Norton, 1999) and it is felt that in depth interviewing fits the grounded theory approach particularly well (Charmaz, 2002). I chose interviews as the method for data collection in this study as they provide open ended in depth exploration of aspects of life where the interviewee has substantive experience and this is often coupled with considerable insight (Charmaz, 2002). The use of interviews fits particularly well with newer sociological approaches to young people and conducting research with young people by acknowledging that young people are social actors who have purpose and who can report on and discuss their own experiences (Mayall, 1999).

Another method commonly associated with the grounded theory approach is participant observation. Through the chosen method researchers aim to see the world as research participants do from the inside. However, as already noted Sartain *et al.*, (2000) have argued that researchers sometimes impose an adult view as proxy for the young person's perspective. I felt the risk of doing so was much greater with the use of participant observations than with the use of interviews. Interviews allow the researcher to pursue topics that respondents define as crucial and this fosters eliciting participant's interpretations of their own experiences (Charmaz, 2006). Charmaz further noted that interview questions ask the participant to describe and reflect upon their experiences in a way that seldom occurs in everyday life and as such I felt the use of

interviews would foster greater insight into the lives of young people than could be achieved with any other method.

A constructivist approach to interviewing stresses that the interview becomes a site for the construction of knowledge and that both researcher and participant produce this knowledge together. The information generated needs to reveal depth, feeling and reflexive thought and researchers need to pay particular attention to language, meaning and participant's lives (Mills *et al.*, 2006²). Grounded theory researchers cannot know exactly what the most significant social and social psychological processes are in a particular setting and so they start with areas of interest to them and form preliminary interview questions to open up these areas (Charmaz, 2002). Grounded theory interviewing differs from much in-depth interviewing because as the research process proceeds the grounded theorist narrows the range of topics to gather specific data for the emerging theoretical framework (Charmaz, 2006).

The type of interview used in grounded theory typically depends on the stage of the research process. The researcher will open up the discussion, listen to participants and use probes to guide them (Duffy, 2004). In this initial phase of the research the researcher will therefore, conduct unstructured interviews. In unstructured interviews the researcher simply has a list of topics they wish to discuss with the participant, which they are free to phrase as they wish (Fielding & Thomas, 2001). It is expected in grounded theory research that interviews may go in unexpected directions as researchers pursue the topics defined as important by participants themselves. During later stages of data collection the researcher asks more focused questions

through the use of semi-structured interviews (Duffy, 2004). In such interviews flexibility is balanced by structure. This challenges researchers to strike a balance between asking significant questions and forcing responses. In order to avoid the forcing of responses researchers must be constantly reflexive about the nature of questions and their suitability for specific participants (Charmaz, 2002).

Charmaz (2006) highlighted that it is important to keep interviews informal and conversational. However, she also noted that novice researchers such as myself may require more structure, which, can be obtained through the use of a well planned interview guide. This she stated can increase the researcher's confidence and permits them to concentrate on what the participant is saying. She further added that the use of a tape recorder can allow the researcher to give their full attention to what the participant is saying. In contrast to this Glaser (1998) cautioned against preconceived interview guides. However, Charmaz (2006) argued that the use of an open ended guide to explore topics is not the same as imposing preconceived codes onto the data collected and that it can in fact help the novice researcher to avoid blurting out loaded questions.

In grounded theory research it is considered most useful to conduct multiple interviews with each participant (Conrad, 1990), as this forms a strong basis for creating understanding of social processes (Charmaz, 2002). However, Charmaz (2006) recognised that numerous researchers face the constraints of time, funding and institutional access which may permit only one interview per participant. She suggested that researchers can attempt to mitigate problems associated with this by ensuring later interviews cover probing questions, which address the

theoretical issues that have emerged from earlier interviews (Charmaz, 2002). For example, when interviewing subsequent participant's researchers may frame questions to allow the participant to make disclosures (Charmaz, 2006).

Charmaz (2006) suggested that in the study of chronic illness it may be beneficial for the researcher to join local support groups and Internet discussion groups to collect additional data. Due to the risk of cross infection young people with CF are discouraged by medical professionals to mix with others with the condition. However, participation in online discussion boards/chat rooms has become common practice in recent years (Moloney, Dietrich & Strickland *et al.*, 2003). A number of discussion boards have been established for young people with CF to participate in such electronic communities. Such discussion boards are accessible to members of the public and I therefore decided to utilise the CF Trust message board for young people with CF as an additional site for data collection.

3.5 Ethics

Conducting interviews poses a number of ethical issues such as: obtaining informed consent; upholding the participants' right to privacy, confidentiality and anonymity; the secure storage of data and overcoming any potential power imbalances between the researcher and the researched (Alderson and Morrow, 2004). Young people have the same rights to confidentiality as adults. However, Alderson and Morrow (2004) pointed out that no one has an absolute right to confidentiality and a breach may be justified in rare circumstances. If a child or young person is

to disclose to a researcher that they are being harmed, the researcher is then obliged to report this to the relevant authority and as such it may not be possible to guarantee the same degree of confidentiality to a young person as it would an adult (Masson 2004). The young person would need to be informed of this prior to giving consent. Currently in the UK the term child is used to describe anyone under the age of eighteen years (Masson, 2004).

In much social research young people under the age of eighteen are not the main givers of consent and it is traditionally parents or caregivers who make the final decision (France, 2004).

Legal and ethical frameworks within the UK rely on the notion of competence but such a concept is problematic and France (2004) argued that it detracts away from the main issue, which, should be to obtain informed consent from young people themselves.

In order to obtain informed consent researchers need to enter into dialogue with young people about the aims and objectives of the research. This requires researchers to provide accessible and readable material that explains the reasons for the research, what the research is trying to achieve, the rights that participants have, their right to withdraw and details of confidentiality, anonymity and storage of data (France, 2004). Researchers have an ethical responsibility to protect participants from harm including emotional harm. This requires a sensitive approach to interviewing and it is essential that researchers be prepared for potential areas of distress (France, 2004).

Further ethical implications are raised with the use of Internet discussion boards. The use of information from such boards has generated concerns about privacy and raises the question of who owns a message posted on the discussion board? (Brownlow & O'Dell, 2002). The messages posted on the CF Trust board were clearly not intended as potential data for research and I therefore, felt it would be unethical to make any specific references to or take direct quotes from them, without asking the young people first.

When interviewing young people it is important for researchers to consider the power dynamics that exist between adults and youth as in Western societies children and young people generally have lower status than adults and consequently less power (Eder & Fingerson, 2002).

Interviewers in particular need to be sensitive to this power imbalance and the way in which, they view young people is pivotal to the power relations that will ensue between the interviewer and interviewee (Robinson & Kellett, 2004). A constructivist approach to interviewing can help to address this power dynamic. Constructivist research perceives young people as subjective, conceptual, self-determining, and dynamic and acknowledges that they are social and relational beings who are engaged in joint action throughout the research process (Greig & Taylor, 1999).

As opposed to the traditional researcher/participant relationship in which, the participant is subordinate to the researcher, undertaking constructivist research commits the researcher to a relationship of reciprocity with participants. Mills *et al.*, (2006²) noted that in order to move the researcher and participant to a more equal position of power the researcher needs to assume a more reflexive stance and adopt a non-judgemental attitude towards those they are listening to.

They highlighted a number of strategies that can be adopted to ensure equal sharing of power these are: scheduling interviews at a time and location of the participants' choice; using a relatively flexible approach to questioning so participants assume more control over the direction of conversation and the researcher sharing personal details with participants and answering their questions.

Reflexivity addresses the influence of the researcher – participant interaction in the research process (Hall & Callery, 2001). Both the researcher and participants will provide unique stimulus for each other, determining what is mentioned and what is not. In the case of interviews the first encounter between the researcher and interviewee means anticipating and recognising the respective other, his/her interests, motives etc. and this will influence the interviewees willingness/unwillingness to participate. During interviews some interviewers may be sensitive to some topics the interviewees offer and ignore or overlook others. Interviewees may only speak about those issues they believe to be appropriate to the researcher and the purpose of the research and consequently their story may be completely different if for example, told to a friend (Mruck & Mey, 2007).

Mruck and Mey (2007) stressed that it is not only what is evident at first e.g. the way a researcher is dressed, that influences the interview but also the more subtle psychological interactions between the persons involved. They further noted that both being familiar and being a stranger will influence data collection and analysis. The more researchers and participants belong to similar cultures, the more interviewers may pre-suppose concepts and values as shared

and therefore fail to attend to elaboration in the interview. Conversely, it is less likely that intimate knowledge will be given to strangers. Gardner (2006) emphasised that each encounter or interview even if concerned with the same topic will produce different data as it is a product of unique circumstances operating at that time. Freshwater (2005) argued that we need to accept the inevitability of bias in any research as the subtle ways in which interaction between the researcher and researched influences the research process can never be fully known or understood.

3.6 Rigour in Grounded Theory

Norton (1999) noted that there are no reliability and validity coefficients in interpretive research. Rather the researcher must be reflexive and consider the impact they have on the researched and vice versa as rigour both necessitates and is determined by reflection on the research process. As such it is important for interpretive researchers to write themselves into their reports via reflexive accounts of the research process and decisions made throughout it and to make explicit their assumptions. Thus, readers are given access to the experience (Norton, 1999). A further criteria for rigour is relationality, which addresses power and trust relationships between the researcher and participants (Hall & Callery, 2001).

Chiovitti and Piran (2003) proposed a number of methods of research practice for enhancing standards of rigour. These fall under three categories: credibility, auditability and fittingness. To ensure credibility researchers can: let participants guide the research process; change

questions on the interview guide as codes develop; use participants' actual words in theory and articulate respondents' views and insights. To ensure auditability, that is the ability of another researcher to follow the methods and conclusions of the research, researchers can specify the criteria built into the researchers' thinking and specify how and why participants were selected. Finally, to ensure fittingness, that is the probability research findings will have meaning to others in similar situations, researchers can delineate the parameters of the research in terms of the sample, setting and level of theory generated.

Glaser (1978) specified a number of criteria for a grounded theory: fit; work; relevance; modifiability; parsimony and scope. However, such criteria suggest that data is treated as a reproduction of reality and is therefore not consistent with the constructivist approach. In line with constructivist grounded theory Charmaz (2006) defined the criteria for grounded theory as:

- **Credibility** – is the data sufficient enough to support the claims made? Do categories cover a wide range of empirical observations?
- **Originality** – are the categories fresh? What is the social and theoretical significance of the work?
- **Resonance** – do the categories portray the fullness of the studied experience? Has analysis drawn on larger social forces or institutions when the data so indicated?

- **Usefulness – does the analysis offer interpretations that people can use in everyday life?**

CHAPTER 4

METHOD

This chapter will outline the methods used at each stage of the present study. It will first outline the preliminary stage of the study and provide a brief overview of the results from this stage.

This section will then provide an overview of the interview stage and the methods used. It will address: sample selection; recruitment procedures; the interview process; providing participant feedback; obtaining medical information; analysis of data and ethical considerations.

4.1 Preliminary Stage

Having identified the area of study to be young people with CF I then conducted a preliminary literature review to identify any gaps in the literature and therefore, justify the need for the research. However, reading was limited to abstracts in order to avoid bias. Through this review I identified the substantive area of transition to adulthood as the focus of study. Through my own background I already held assumptions of what the transition to adulthood meant and involved and therefore, what the areas of importance may be for young people during this time. However, in line with both the establishment of a new orthodoxy that encourages us to listen to young people and the grounded theory methodology in general I wanted to ensure young people with CF themselves were able to shape the research agenda and thus, identify the areas important to them.

I initially hoped to conduct a preliminary stage of focus groups with young people with CF. Due to the risk of cross infection I proposed to do this via the internet. However, I was unable to obtain ethical approval to do this due to the risks to confidentiality and security posed by use of the internet. I therefore, decided to access young people with CF via the CF Trust Internet Message Boards. With the permission of the CF Trust I posted a message on the board for teenagers and young people with CF and invited them to respond (appendix 1). The message gave details of the study and asked the young people to provide feedback on the areas of transition I had identified as important. It asked the young people whether they felt these areas were important and to identify any further areas they felt worthy of study. The message explained that any responses would be used in the study to devise the initial interview topics

4.2 Interview Stage

4.2.1 Sample

Sampling was initially purposive. I had no specified external criteria however; all participants had to have knowledge and experience of the phenomena under study. Therefore, participants needed to have CF and be currently going through the transition to adulthood. The transition to adulthood is generally thought to begin around the age of 16 years and continue into the early 20's (Barnados, 1996). Ethical approval was sought to recruit participants over the age of 16 years from a CF Department, at a regional children's hospital (appendix 2).

As initial data was collected and analysed, decisions were made about the sample based on emerging theory. Based on the emerging theory I decided that I needed to interview additional participants who were further on in the transition to adulthood and hence older. I decided to extend the study to include young people with CF who had already moved to an adult CF department and therefore, obtained ethical approval to recruit participants from a CF Department for adults, at a regional hospital (appendix 3).

Data collection was carried out over a period of one year and ceased when the core category and all other salient categories had become saturated. A total of thirty-five potential participants were approached and eighteen were recruited, ten females and eight males, all between the ages of 16-21 years. The main reasons cited for not wanting to participate were not having the time and finding it too difficult to talk.

4.2.2 Recruitment

The same recruitment procedure was carried out within each of the two settings. Initially staff in the CF Department identified all potential participants currently attending the CF clinic. I was then given a list of clinic dates to attend when potential participants would be attending. The young person, and in the paediatric setting, a parent or guardian were initially approached by one of the CF nurses. They were asked if they were willing to talk to me about the research. For those who were willing I then spoke to them and a parent/guardian where appropriate. At this point I explained the purpose of the study and what their role would be should they choose to participate. I then gave them a detailed information sheet (appendix 4) to take away with them.

For those attending a paediatric clinic a parent information sheet was also given to the parent/carer with them at that time (appendix 5). I then asked the young person whether it would be okay for me to take a phone number and phone them in a week's time to see whether they would like to participate. At this point it was stressed to the young person they were under no obligation to give me a phone number or to participate. A total of twenty seven young people were happy for me to phone them. The other eight chose not to participate there and then.

I phoned those who had provided me with a phone number one week later to ask them if they would like to participate. At this point I asked the young person if they had any questions they would like to ask me. A total of eighteen young people agreed to participate, with nine choosing not to. For those who agreed to participate I then arranged a convenient time and place for them, to conduct the interview. The majority of participants chose to be interviewed within the CF Department in a private room. Three participants chose to do the interview in their homes

4.2.3 Interviews

I devised an initial interview guide based on the responses to the message posted on the CF Trust board (appendix 6). A total of nine responses were posted on the message board. The message had identified the major areas of transition to adulthood as: transition from school to further education, employment or training; transition to financial independence, transition to independent living and transition from paediatric to adult care. It also identified the people I perceived as having an influence on the transition to adulthood as family and friends and the places as school and hospital. The young people were asked whether they agreed with this and

what additional factors they felt were involved in and would affect the transition to adulthood.

None of the responses disagreed with the factors I had identified as important.

All of the respondents agreed that the transition to adulthood consisted of the major areas I had identified. Three specifically mentioned the importance of friends and four mentioned the importance of family. Six also highlighted the importance of hospital staff in making the transition in both negative and positive ways. Two respondents mentioned the role of the school and seven mentioned the role of the hospital in making the transition to adulthood. One transition of particular concern was the transition to adult care with five of the nine respondents talking of the difficulties associated with this.

The only issue to arise that I had not previously considered was that of mentorship. One respondent highlighted the potential benefits of having the support of an adult with CF who had themselves already negotiated the transitions identified. Subsequently a further two respondents agreed this was a good idea. Following analysis of these results I ensured all of the issues raised in the responses were incorporated into the interview topics.

Therefore, the guide consisted of a broad set of topics for discussion. All participants agreed to have their interviews tape-recorded. At the beginning of each interview I stressed to participants they could talk freely about anything they felt was important.

Initially interviews were unstructured and aimed at getting participants to open up and identify what was important to them. As data collection progressed the interviews became more focused and hence semi-structured. I altered the interview guide accordingly with ongoing analysis in order to subsequently collect data to elaborate and refine categories in the emerging theory. All interviews lasted between one and two and a half hours. I ensured all interviews ended on a positive note by ensuring the final questions asked were slanted towards positive responses.

I had initially hoped to conduct follow up interviews with each participant after one year. Unfortunately this was not possible due to time restraints. I therefore ensured I used probing questions in later interviews to address theoretical issues that had emerged in prior interviews.

4.2.4 Feedback

Following initial analysis I provided participants with written feedback on their interview. I invited participants to give their thoughts and opinions on the initial interpretations that had been made (an example of this can be found in appendix 7).

4.2.5 Medical information

All participants gave permission for a CF nurse specialist to provide me with information from their medical records in order to obtain a measure of disease severity. I was provided with the result of each participant's most recent respiratory function test (FEV1). Participants were assured I would have no direct access to their medical records.

4.3 Table 1: Sociodemographic and clinical variables of participants

Participant number	Gender	Age	Pre or post transition to adult care	Latest FEV 1 score (%)	Disease severity ranking*
1	Male	17	Pre	50	4
2	Female	17	Pre	96	17
3	Female	17	Pre	89	16
4	Female	17	Pre	57	8
5	Male	17	Pre	79	14
6	Female	16	Pre	64	11
7	Female	17	Pre	51	5
8	Female	16	Pre	29	1
9	Male	18	Post	65	12
10	Female	20	Post	82	15
11	Male	21	Post	115	18
12	Female	18	Post	30	2
13	Female	19	Post	56	7
14	Male	20	Post	67	13
15	Female	18	Post	63	10
16	Female	18	Post	40	3
17	Male	18	Post	61	9
18	Male	20	Post	55	6

*Participants were ranked by disease severity according to their latest FEV1 score with 1 being the lowest score and thus the greatest disease severity and 18 being the highest score and thus the lowest disease severity.

4.4 Analysis

4.4.1 Sensitising concepts

Through my own academic background in childhood studies and having worked with disabled children and young people for a number of years I have developed an awareness of the disability literature. An awareness of this literature provided me with a number of sensitising concepts to use as starting points when looking at the data. However, I was very conscious of not forcing data into preconceived codes and categories and any concepts that were utilised had to earn their way into analysis. The disability literature is largely concerned with the impact of larger social forces on the lives of disabled people. I feel this encouraged me to consider the macro influences as well as micro influences in the lives of participants when collecting and analysing data.

4.4.2 Coding and categorising

I transcribed all interviews into the qualitative computer package Nvivo as soon as possible after the interview had been conducted. Analysis began after the first interview and was carried out simultaneously with further data collection. I had initially intended to adopt the coding approach

as advocated by Glaser (1978; 1992; 2004) as I felt this was flexible and as such more consistent with a constructivist approach. However, it soon became apparent that as a novice researcher I needed a more structured approach to data analysis. I therefore, decided to use the coding approach of Strauss and Corbin (1990; 1998). This provided me with detailed guidelines for coding including the use of a coding paradigm. In order to retain some flexibility I chose which of Strauss and Corbin's (1990; 1998) guidelines to use and used only those I felt were necessary.

I initially carried out open line-by-line coding on all data, which helped me to identify implicit concerns and explicit statements (Charmaz, 2006). I used in vivo codes to help prevent the imposing of preconceived beliefs on to the data. The data was initially coded for concepts, which were eventually grouped together into categories. I then undertook axial coding where I began to link categories with their subcategories. I used the coding paradigm as described by Strauss and Corbin (1990; 1998). This was particularly helpful in aiding me to organise data.

The final stage of coding used was selective. I first decided on a core category and I then started to integrate it with all the other categories and hence, began to build a substantive theory. The core category appeared frequently within the data and was central and thus related to all other categories. Coding was not conducted in a linear fashion and often shifted between the different levels due to the use of the constant comparative method. Strauss and Corbin (1990; 1998) also developed a further coding device; the conditional/consequential matrix. I chose not to use this coding device as I felt it was unnecessary and restrictive.

Throughout the process of data collection and analysis I regularly wrote theoretical memos in order to keep a reflexive account of the research process, data analysis and emerging theory. This enabled me to keep track of all the decisions made in the process of the research. I wrote memos to capture ideas and theory development.

4.5 Ethical Considerations

Ethical approval was obtained both from Liverpool John Moores Ethics Committee and Liverpool Paediatric Research Ethics Committee. When the decision was taken to extend the study to include a second NHS trust both ethics committees were notified of the planned substantial amendment and subsequently both gave their approval. The research protocol was reviewed and approved by both NHS trust sites.

The ethical considerations of the study were addressed using the following measures:

- Potential participants were given a detailed information sheet that included information on the purpose of the research, the procedure and participants role, the participants right to withdraw, ensuring confidentiality and anonymity, storage of data, information that would be obtained from their medical records and what would happen with results of the study

- On the instruction of the Liverpool Paediatric Research Ethics Committee for those participants recruited through the paediatric setting their written assent was obtained (appendix 8) and the written consent of a parent/guardian (appendix 9). For those recruited through an adult setting the written consent of the participant was obtained (appendix 10).
- To minimise disturbance to routine interviews were conducted at a time and location of the participants' choice
- Potential participants were given at least one week to consider whether they wished to participate
- All tapes and notes were anonymised and stored in a locked cabinet on secure premises
- Prior to research beginning at each site, links were made with a number of staff members including nurse specialists, consultants and psychologists whom participants could be referred to if they became distressed as a result of the research
- It was explained to all participants that anything they said would remain confidential unless I became concerned for their safety or well-being at which, point I would discuss with them the need for additional support and with their permission refer them to an appropriate member of staff

- Due to the ethical implications of using information from the CF Trust internet discussion board without the consent of the authors I decided to post a message on the board, which, specifically asked young people with CF to respond. The message explained to the young people that their responses would be used in the study

4.6 Rigour

A number of measures were taken to minimise the potential for researcher bias. The initial interview topics were devised from consultation with young people with CF and the use of grounded theory methodology ensured interviews focused on issues of importance to the participants. Participants were given written feedback following their interview and invited to give their thoughts and opinions on the interpretations made. Finally, a selection of the anonymised data was co checked by a supervisor.

In line with constructivist methods I was very aware of the power dynamics between participants and myself. I tried to make the interview setting as relaxed and informal as possible and as such I felt it was important to dress casually for interviews. I began each interview by explaining to participants that my background is non-medical and as such I do not have a vast knowledge of CF as a medical condition. Furthermore, when participants spoke of medical issues I asked them to explain things to me reinforcing that in that interview situation they were the experts on CF. I felt this helped to achieve a more equal distribution of power. I was happy to engage in conversation with participants, share personal details and answer any questions they asked me. I

was consciously aware of adopting a non-judgemental stance throughout the interviews, particularly so when participants spoke of issues such as non-adherence to treatment. During such times I would simply listen to participants and if necessary assured them what they were saying was confidential.

I ensured that throughout the research process I engaged in reflection, considering the ways in which both myself and the participants influenced the research process. My initial encounter with participants took place in a hospital clinic. I was therefore aware that participants may assume they were being asked to participate in medical research and this may affect their willingness to participate. At this point I stressed to the participants that I simply wanted to talk to them about their experiences and that the research was in no way medical.

During the initial interviews I became conscious that the participants may have felt obliged to talk primarily about issues relating to their health and health care, perhaps as most of the interviews took place in the hospital setting. This was particularly evident in that when participants were initially asked what the transition to adulthood meant to them they would then speak at length about the transition to adult care and require probing to move onto issues not directly health related. Having realised this may be the case in subsequent interviews I began by stressing to participants that I was interested in whatever issues were important to them and that they should feel free to talk about all areas of their lives not just those that were health related if they so wished. I feel doing so enhanced subsequent interviews as participants spoke much more openly and freely about non health related issues. A number of the participants acknowledged

that this was something they rarely had the opportunity to do and thanked me after the interview for giving them the opportunity to do so.

I was aware that being a stranger to the participants would influence the interview process. At times some of the participants made comments about a person without CF such as myself not being able to fully understand the experiences of someone living with the condition. I felt that in such situations it was important for me to acknowledge to the participant that as a person without CF I was aware that I could never understand what it meant to live with the condition, as to claim otherwise would have potentially belittled their own views and experiences. I then explained to the participants that I simply wanted to know about their own experiences, views and feelings on issues of importance to them.

Being a stranger to the participants and being a person without CF also held some advantages as I did not pre-suppose that I shared the same experiences, values and beliefs as participants. This encouraged me to invite participants to elaborate on their experiences in order to enhance my own understanding. I feel that knowing relatively little about CF prior to the research process allowed me to be very open to new topics as they emerged as I did not hold pre-conceived beliefs about what the issues of importance would be to a young person with CF.

Following each interview I had a debriefing with a supervisor and this gave me the opportunity to reflect upon the individual interviews, issues of importance that had arisen and on my own

reactions to participant's responses. Doing so allowed me to consider the ways in which I could for example, better handle certain topics or encourage participants to be more open in subsequent interviews.

CHAPTER 5

RESULTS

This chapter will provide an overview of the ways in which data from the present study was analysed. It will provide a short summary of the seven salient categories identified through analysis before outlining the development of the core category. It will then discuss the presentation of results for a grounded theory and outline how the results of the present study will be presented. Finally, the findings of the study are presented according to the core category and the three subgroups identified from it.

5.1 Data analysis

Data was analysed using the coding guidelines outlined by Strauss & Corbin (1990; 1998), reviewed in section 3.3.4. Coding began after the first interview had been transcribed and continued throughout the data collection process and after. Initial open coding identified a number of concepts through the use of line-by-line coding. These were eventually grouped together into 7 salient categories, all of which stood for a particular phenomenon and were able to depict a particular problem, issue or concern to the participants. These are listed below with a brief summary of the problem, issue or concern depicted by the category:

- **Being normal** – being normal and leading a normal life was of primary importance to these young people. The notion of normality held very different meanings and connotations for the young people and the ways in which they conceptualised normality within the context of their own lives had far reaching consequences.
- **Becoming an adult** – the young people all spoke of their hopes and aspirations for the future. However, they differed in the extent to which they felt these could be achieved and the impact of CF in doing so. They spoke of both internal and external factors that may help or hinder them in achieving their goals.
- **Telling others** – disclosing their condition to peers was a concern for the participants. They displayed a wide range of disclosure patterns ranging from not telling any peers about their CF to openly telling anyone no matter how well they knew them. For some disclosure was a spontaneous event whilst for others it occurred only after very careful consideration.
- **CF and me** – the young people varied in the extent to which they felt that CF constituted a part of their personal and social identity. Whilst some felt that having CF was a positive aspect of whom they were others rejected this notion. This was affected by a number of factors including their level of desire to be seen by others as normal.
- **Being supported** – the young people had experienced varying levels of support and this was particularly evident in making and being prepared for the transition to adult health care.

Support in relation to their CF came from a variety of sources but they varied in the extent to which they wanted support from others. Whilst some readily accepted support when they felt they needed it others rejected any offer of support that they felt may separate them from their peers and portray them as somehow different. Some of the young people felt the support they received was inadequate.

- **The role of treatments** - all of the participants spoke to some degree about the burden of their CF treatment regime. They expressed a wide range of views about the role of CF treatments in their lives. This was reflected in the varying levels of adherence to treatment regimes that the participants reported. Attitudes to treatment were related to the level of control the young people felt they had over their condition.
- **Coping with CF** – the young people identified a number of coping responses that they used to deal with their condition and its related issues. These included both active and passive responses as well as both problem-focused and emotion-focused strategies.

Data from each of the participants was compared to ensure that the categories held relevance and were applicable to all the participants in the study. The categories were then developed through the use of axial coding. Sub-categories were identified that were able to answer questions about the categories such as when, where, why, how and with what consequences? This was achieved through the use of the coding paradigm outlined in section 3.3.4. The coding paradigm was used to consider the conditions that created each of the categories, the actions and events that arose

under those conditions and finally the consequences of those actions/interactions. Further data collection allowed the categories to be filled out and refined until saturation was achieved.

Selective coding was carried out to try and integrate the categories into theory. The first stage was to select a core category. The category 'being normal' was chosen as it represented the main theme of the research. It was the most central category appearing frequently in the data and was able to pull all the other salient categories together. It was also able to account for much of the variation in other categories. In order to ensure I had chosen the right core category I shifted back to open and axial coding to specifically address how each of the other categories related to it. This allowed me to develop each of the salient categories according to the core category and thus the 3 different conceptualisations of normal portrayed by the participants.

5.2 An example of the coding process – development of the core category

Below is a brief overview of how the core category was developed throughout the coding process. This is to provide an example of how categories emerged and were developed and it also demonstrates the reasons why this category was selected as the core category.

Through initial line-by-line coding I identified the concept of normal. The word normal appeared frequently in all of the transcripts. It was something all of the participants had spoken about without being prompted to do so. The participants spoke of normal in a number of

contexts; they spoke of being a normal person and the place of CF within this and they also spoke of leading a normal life and what if anything they felt they had to do to achieve this. All of these concepts were grouped together into the category entitled 'being normal'.

Through axial coding I began to look at the category in more depth. It was apparent that the concept of normality was a pertinent issue for all the participants at this stage of their lives. However, as analysis progressed it also became evident that the concept of normal and normality held different meanings and connotations for them.

All of the participants spoke of living a normal life and I tried to look beyond surface meanings to interpret the implicit meanings of their statements. I asked questions of the data such as what is going on here. What does being normal mean to this young person? What does leading a normal life mean to this young person? Under what circumstances have these views arisen? How does this young person's conceptualisation of normal affect their actions? What are the consequences of such actions? Asking these questions allowed me to uncover the array of meanings and experiences alluding to their statements.

By comparing data from each of the participants it became apparent that within this category the young people fell into three distinct subgroups. The subgroups represented three very different ways in which the young people conceptualised being normal, living a normal life and the

subsequent actions and consequences that arose from this. All but one of the participants fell into one of the subgroups, these were:

- **Subgroup 1 - I am normal:**

For these participants having CF is a normal part of their lives. Whilst recognising that others may not view their lives as normal, to them it is all they have ever known:

“I’m just a normal and like bubbly person I still go to school and socialise and like I just get on with it you know cos I’ve never known any different” (female, aged 16).

“You can still have a normal life and at the end of the day everyone’s got their problems to deal with” (male, aged 21).

“I mean it’s not like when someone gets cancer or something its different cos I’ve always had CF and to me it’s just a normal life really say someone who hasn’t got CF might not think my life is a normal one but to me it is it’s just like all I’ve ever known” (female, aged 17).

These participants spoke of having good support networks and having been encouraged to be independent by both family members and health care professionals. They spoke of the importance of having a positive attitude but this did not equate to denial of their CF. They felt having a positive outlook could help them overcome any potential barriers that having CF may present in the transition to adulthood:

“You’ve just got to be positive you know and try and get on with life and I mean yeah there will be times when things go wrong but you’ve just got to stay positive and try and get over them”
(female, aged 17).

These young people expressed similar hopes and aspirations for adulthood as their peers and they were all still in some form of education, school, college or university. They all had plans for their future but acknowledged they may need additional support when their health began to deteriorate. They were happy to accept support from family, friends and professionals when they needed to. They viewed this as a normal part of life for someone with CF:

“Sometimes you know like you will need a bit of extra help like say if you get a place of your own and then you get really sick then you are gonna need extra help but it’s like people with CF know that really it’s just part of having CF isn’t it?” (male, aged 19).

For these participants having a sense of control over their CF was important to them. Whilst they acknowledged that at some point their health would inevitably deteriorate they still felt that their health status was partly controllable by them. They largely equated this to adhering to their prescribed treatment regimes. Treatment was seen as a priority as it helped them to stay healthy and thus achieve their goals. They also ensured they were in control over which of their peers knew about their condition, what they were told and when. They acknowledged that having CF was a big part of their lives but felt that it did not define who they were:

“Yeah I’ve got CF but that’s not just what I’m about it’s a big thing yeah but it’s just one part of my life you know” (female, aged 17).

- **Subgroup 2 - Striking a balance:**

For these participants living with CF was not a normal life. However, they felt that someone with CF could and should try to live as normal a life as possible. It was about striking a balance between the CF and other areas of importance in their lives such as work, education, family, friends and partners. They spoke of how this could be a struggle at times and something that required a lot of effort on their part:

“My health is a priority but it’s like trying to balance everything out like work, health, university, social life, love life and it can be really hard, sometimes you get it right but sometimes you don’t and you end up in hospital” (female, aged 20).

“I do have responsibilities other than me health and obviously I do try an keep myself healthy but at the same time I have got a life, I’ve got a social life and I work and that’s important too” (male, aged 20).

“It’s not normal living with CF all the things you have to do and think about and you’ve gotta like balance the CF with everything else like work and college and a social life” (female, aged 17).

“You’ve just gotta try and live as normal a life as possible really and just get on with things that’s all you can do” (female, aged 17).

These participants said they would like more support but were unsure where to get it from. They tried to maintain a positive attitude but found this difficult at times. They didn’t like to burden others such as their friends and family, with their CF related problems and at times they felt very isolated:

“It’s hard you know cos like you don’t want to worry anyone else with it but sometimes you just need someone to talk to about stuff but there is no one” (Female, aged 18).

“I think the worst thing is that it can just be so lonely sometimes when you feel like there’s nobody you can talk to about it” (male, aged 20).

“You’ve got to try and stay positive but sometimes it’s hard ... things just get on top of ya”

(female, aged 20).

These participants also had similar aspirations for the future as their peers. However, they expressed some fear of making plans for the future and they were unsure of the impact that CF would have on them achieving their goals.

“You’ve got all these things you wanna do you know just like all your mates have but really you just don’t know what’s gonna happen with the CF You don’t know when your health’s gonna start going downhill” (female, aged 17).

Whilst acknowledging the importance of adhering to their treatment regimes they felt that sometimes it was not possible to do everything. Again this was about striking a balance between keeping well but not allowing this to be at the expense of a normal social life. Therefore, they were willing to take considered risks with treatments:

“If you did everything you’re supposed to then there’s no way you could have like a normal social life you’ve just got to make your own choices about it you know” (female, aged 20).

“It’s like when you get to my age you kinda know what you can get away with not doing so you just do what you have to to keep well” (female, aged 17).

- **Subgroup 3 - I want to be normal:**

For these participants having CF is not normal, it is something they fear could prevent them from leading a normal life and being perceived by others as normal. They spoke of their desire to lead a normal life and described the lengths they would go to in order to achieve this. For these participants normal is being able to act and behave like their peers without having to worry about the implications of this for their health. Social life and activities with peers are of primary importance:

“I just wanna go out with me mates and just have a laugh and like go to footie practice, just everything that’s normal really like what normal teenage lads do” (male, aged 17).

“My mates are my priority really like and if you’d rather be doin something other than treatment then you should just do it and just enjoy your youth, that’s what I’m doin” (male, aged 17).

“I just reckon if you wanna do something then you can’t let the CF get in the way I’m only young you know I just wanna go out with me mates and have some fun” (female, aged 18).

There was a fear of being viewed by their peers as different and hence stigmatised:

“I don't want people to think I'm different there's no need for it I just wanna lead a normal life ya know” (male, aged, 18).

“I don't want people being funny with me or feeling sorry for me cos of the CF I'd hate that” (female, aged 18).

These participants expressed a preference to deal with issues or concerns on their own and had often refused support offered to them from various sources. They felt that other people placed too much emphasis on their CF when they just wanted to try and forget about it. Whilst they did hold aspirations for their futures they were apprehensive about making plans due to the progressive nature of CF. Despite this they spoke of being non-adherent on a regular basis as treatment was seen as something that separated them from their peers. Not doing treatments was a way of living a more normal life. They did not feel that CF was something they could control in any way but not doing treatments was one way of maintaining some control over their lives more generally:

“I know personally that say twenty years down the line I will either be dead or very ill and ya know I could spend all this time now doin treatments but at the end of the day it might not make any difference and ya could be missin out on doin just normal teenage stuff like hanging out with mates playing footie and goin the pub and it could be for nothin it's still gonna kill ya, you've just gotta enjoy your life now you know ” (male, aged 17).

As shown in table 2, section 5.4, each of these subgroups comprised both males and females and both pre and post transition to adult health care and with a range of disease severity rankings. Throughout the coding process I was aware of the possibility that socio-economic status may have been a contributing factor as to which of the subgroups participants fell in to. However, it was not possible to consider this as no measure of socio-economic status had been obtained for the participants.

Once the subgroups had been identified I then developed them further with the use of the coding paradigm. This encouraged me to consider the conditions, actions/interactions and consequences of each subgroup. Through consideration of these aspects I began to uncover the ways in which this category was related to the other salient categories that had been identified. It became evident that this category was related in some way to all of the other salient categories. Placing the participants into the three subgroups meant that this category was able to account for much of the variation in other categories thus emphasising that the ways in which participants conceptualised being normal and leading a normal life had far reaching consequences in many areas of their lives.

Once I began selective coding I was confident that this category should be selected as the core category for a number of reasons. Firstly, this category had appeared frequently in the data, in discussing the transition to adulthood the young people had repeatedly spoke of being normal and leading normal lives without being prompted to do so. Therefore, it was clearly a very pertinent issue in their lives.

Secondly, this category was the most central of all the categories. It was related to each of the other categories and able to account for much of their variation. To ensure this, once I had selected the core category I then shifted back to open and axial coding to address its relationship with each of the categories. In doing so I was able to specify how this category and the subgroups within it are related to and able to account for variation within the other salient categories.

Thirdly, I was confident that this category was sufficiently abstract so that it could be used to do research in other substantive areas. For example, it could be used in research with young people with a chronic illness other than CF. Finally, and perhaps most importantly, this category was able to pull the research together and I felt it represented the main theme of the research.

5.3 Anomalies

One participant did not fall into any of the three subgroups however; she spoke of very different circumstances to any of the other participant's. Having been bullied at mainstream school this participant attended a special needs school. At school there were nurses who had responsibility for her treatment regime and she spent every school holiday in hospital. She explained this was because her family did not and had never played any role in her treatments so they had to be done either in school or hospital. She explained that spending time in hospital felt normal to her and was not something that bothered her. The hospital was a place she felt looked after and

cared for and therefore she did not seem to mind spending so much time there. She had built up close relationships with staff in the hospital and even referred to some as her family:

“I don’t mind comin in the staff are great ... they’ve always been here for me, Mo’s been here since I was a baby I call her Aunty Mo cos she’s like family to me really” (female, aged 16).

“It’s just normal to me now cos I’ve always come here and I don’t mind it really they all look after me and talk to me all the time and that so it’s fine really.”

She liked to talk to others with CF whilst in the hospital. However, she spoke of having no friends in school and only one friend out of school. She felt her only source of support came from hospital staff:

“I just talk to the staff here really like I can tell them anything they’re great Sometimes I talk to other people when I’m in here you know like other CF’ers but I don’t see them outside of here or anything.”

“Well I wouldn’t really say I was mates with anyone in the school really I only see them in school but I’ve got one mate out of school who I hang round with sometimes but she’s younger than me I think she’s twelve.”

She had not given much thought to the transition to adulthood in general. She felt unable to make plans for the future due to her poor health:

“I don’t know what will happen in the future really I just don’t know cos I get sick really quickly ...I haven’t really thought about what I will do after school like I don’t know if I could have a job or a flat or anything cos I’m in here (the hospital) so much.”

She felt anxious about her impending move to adult health care and leaving the hospital where she had built such close relationships with staff members:

“I know everyone’s gotta go someday but I’ll really miss the nurses here they’re like my family ... I wish I could just stay here really.”

5.4 Table 2: Sociodemographic and clinical variables of participants by subgroup

Subgroup	Gender	Age	Pre or post transition to adult care	Latest FEV 1 score (%)	Disease severity ranking
1	Female	17	Pre	96	17
1	Female	17	Pre	57	8
1	Female	16	Pre	64	11
1	Male	21	Post	115	18
1	Male	19	Post	56	7
2	Female	17	Pre	89	16
2	Female	17	Pre	51	5
2	Female	20	Post	82	15
2	Male	20	Post	67	13
2	Female	18	Post	40	3
2	Male	20	Post	55	6
3	Male	17	Pre	50	4
3	Male	17	Pre	79	14
3	Male	18	Post	65	12
3	Female	18	Post	30	2
3	Female	18	Post	63	10
3	Male	18	Post	61	9
N/A	Female	16	Pre	29	1

5.5 Presentation of findings

Strauss & Corbin (1990; 1998) stressed that the findings of a grounded theory study should be presented as a set of interrelated concepts and not just a list of themes. It is therefore important that during selective coding the researcher moves away from pure description and begins to consider the data on a more abstract level, with the ultimate goal of developing theory.

Charmaz (2006) noted that a constructivist approach does not attempt to explain one reality; it sees multiple realities and asks what people assume is real and how they construct and act upon their view of reality. To achieve this analysis must go beyond surface meanings to look at how and why participants construct meanings and actions in specific situations. A constructivist approach places priority on the phenomenon of study and see both data and analysis as created from shared experiences and relationships with participants. The process of theorising should foster seeing possibilities, establishing connections and asking questions.

Strauss and Corbin (1998) suggested that the final conceptualisation of the core category and all other categories could be presented as a storyline that fits all the stories/data it represents. The story is told using all the different categories and their linkages. Relationships between categories are implied rather than written in a cause and effect fashion but all other categories should fit logically with the core category. This final conceptualisation should fit the data and offer an interpretation of what the research is all about.

Taking into account all of the above I attempted through selective coding to integrate all of the salient categories with the core category to develop a storyline for each of the three subgroups identified. However, having read a number of grounded theories I was concerned that presenting the findings as a story would overlook the individual differences between participants and the variation within categories. I did not feel that presenting the findings as a flowing and uninterrupted story could incorporate the insight obtained from all of the participants interviewed. I attempted to overcome this by using direct quotations from all of the participants throughout the findings to illustrate the points being made. This ensured that the story being told held relevance for all of the participants.

5.6 Findings of the present study

Findings are presented below under the 3 subgroups that developed from the core category.

5.6.1 Subgroup 1 - I am normal

For these young people a life with CF is a normal life, it is all they have ever known. To outsiders their lives may not appear to be normal but to themselves and their families CF has become simply a fact of life. One young male distinguished between having lived with a chronic condition all your life, as most people with CF have, and acquiring a condition after having the experience of living without it:

“I mean it’s not like when someone gets cancer or something its different cos I’ve always had CF and to me it’s just a normal life really, it’s not like you have to get used to having it, you’ve always had it and its always been part of your life, say someone who hasn’t got CF might not think my life is a normal one but to me it’s just like all I’ve ever known” (female, aged 17).

CF is a stable part of their identities and is something that provides shape and meaning to their lives. Having a chronic condition has altered their outlook of life and has helped to shape who they are and who they are becoming:

“I think havin CF just makes you think about things differently you know like you just make the most out of things and try and enjoy life to the full” (male, aged 19).

“I guess CF has kinda helped shape who I am and I mean that in a positive way cos through all my experiences its helped make me who I am and I’m happy with who I am and I don’t think I’d be that person if I didn’t have this” (male, aged 21).

These young people did not express a desire to be normal or lead a normal life – they explicitly stated that they are normal and they do lead normal lives. CF is one part but not all of that normal life. Having always lived with this condition they could not imagine their lives without it:

"I am normal ya know this is a normal life to me it's all I've ever known" (female aged 17).

"I can't imagine what life would be like without CF really cos I've always had it it's just part of who I am" (male, aged 21).

They had constructed their identities, not through the sidelining of their condition but through the reconstruction of normality. For some this was a subconscious process but others had questioned the meaning of normality as they came to realise that others did not view their lives as normal.

The conclusion - being normal means different things to different people. For these young people it included living and dealing with CF:

"I've just never really thought about it I don't know I guess it's just become like normal to me cos I've never known any different" (female, aged 16).

"I mean when you think about it what is normal? I mean obviously what's normal to me won't be normal to someone who hasn't got CF so really it just depends on the individual... say like what's a normal life to you isn't the same as a normal life to me so like we've both probably got really different lives but we both think they're normal don't we?" (female, aged 17).

CF is an important part of their lives it is something that requires both thought and action on a daily basis but it does not define their lives. It has helped to shape but does not define who they are, as one participant explained:

“CF is a big part of my life you know it’s part of who I am but that’s not just it erm, I don’t know how to explain it it’s hard but it’s just like CF’s not me you know if that makes sense it’s not all that I am and it doesn’t mean that I can’t live my life how I want to does that make sense?”
(female, aged 17).

It was possible to feel both normal and different at the same time. Having CF made their lives different to those of their peers but these differences did not impact on their ability to live their lives how they wished and were therefore embraced:

“I mean yeah there’s things you have to do you know like treatments and just planning ahead that say my friends don’t have to do but it doesn’t stop me havin a normal life not at all” (male, aged 19).

“It does make you different in some ways but so what you don’t wanna be the same as everyone else do you?” (female, aged 17).

The need to carry out a daily treatment regime was perceived to be the way in which their lives differed most notably to the lives of their healthy peers. However, it was also a means by which, the young people felt able to maintain a sense of control over their condition and consequently they adhered to their treatment regime most if not all of the time. Maintaining a sense of control was the primary way in which, they coped with their condition and its implications. Having CF was not something they could control but doing treatments and keeping themselves well allowed

them some element of control:

“Doing the treatment gives you some control cos you know if you don’t do it you’ll get ill but if you do it then you can keep yourself in the best health that you can be” (female, aged 17).

“I think that it’s at least partly in your control ya know I mean yeah there’s times ya get sick and ya can’t stop that happenin but if you do ya treatments and keep yourself well then ya can have some control over it all” (female, aged 17).

Treatment was very much a priority in their lives. It was seen as a facilitator rather than barrier to being normal and leading a normal life. It was not a burden or a chore but part of their normal everyday routine:

“It’s just become a routine now I just don’t think anythin of it it’s just like brushing your teeth in the morning” (female, aged 17).

The positives of doing treatments were perceived to far outweigh the negatives. Establishing routines, preparation and planning ahead were strategies employed in order to minimise the impact of treatment regimes:

"I prepare my tablets on a weekly basis cos it's a lot easier ... it's just a case of preparation and being organised ... It's never stopped me doin anything you just have to plan ahead sometimes"
(male, aged 21).

"You've just gotta get into a routine with it ya know and that way you don't think about it it's just like part of your normal day" (male, aged 19).

"You just have to plan ahead like if you know you're gonna be goin out that night then you make sure you start your treatments earlier" (female, aged 16).

Treatments did not provide a magic answer or a cure but allowed the young people to establish and maintain their optimal health status. Doing so fostered hope that they could achieve their many aspirations for adult life. This also drove them to seek additional ways of keeping well, such as exercise. In the grand scheme of things adhering to their daily treatment regime was a small price to pay if it meant keeping themselves as well as possible for as long as possible and they expressed their gratitude that they were able to do so:

"It's important cos like it's keeping me healthy and at the end of the day you know there's things I wanna do, I do wanna go to uni and get a job and maybe get married one day and I know the only way I can do that is by keeping as healthy as I can" (female, aged 17).

“I feel lucky really that at least I can do these treatments and they help keep me well I just don’t understand why people wouldn’t do them it’s just stupid and I’m just grateful really that they’re available ... I’d do whatever the hospital told me to if it was gonna help keep me well” (female, aged 17).

Maintaining a sense of control required the young people to assert their independence.

Becoming an adult entailed becoming less dependent upon others and with the encouragement of family members and healthcare professionals the young people had gradually taken over the responsibility for their own health care:

“It’s my responsibility ... it’s been like that for the last three years just gradual you know with me taking more responsibility” (female, aged 17).

“My mum and dad and like the nurses and doctors they all encouraged me to take responsibility ... At first they would check on me but they trust me now” (female, aged 17).

Once personally responsible for their own health care they were reluctant to let anything undermine this, one participant spoke of how she had refused to hand in her medication in school:

"I remember in school they said I would have to give my tablets in to the office but I was just like no cos at the end of the day it's my responsibility and I know what I need to take and when ... My parents backed me up on it and in the end the school just said okay" (female, aged 17).

Taking responsibility for their own health care represented an important step towards becoming an adult and one that was positively embraced. It constituted important preparation for the transition to adult care, as one participant stated:

"It's just something you have to do you know part of becoming an adult and it's a good thing especially for moving over to the adult clinic, you have to take responsibility for yourself" (male, aged 19).

The transition to adult care was an important stage in the transition to adulthood and a positive milestone:

"It's a good thing really cos it's all just part of becoming an adult" (female, aged 17).

"You've just gotta see it as a positive step ya know just part of growin up" (female, aged 16).

Health care professionals were highly trusted and this trust was deemed to be reciprocal. The young people trusted that the advice given to them was in their best interests and felt they were trusted by both health care professionals and their parents to follow this advice:

“At the end of the day I trust my family and I trust the staff if they’re telling me to do something say like a new treatment then I know it’s for me own good” (male, aged 19).

CF nurse specialists were of particular significance and played a key role in the lives of these young people. Their role was not merely a medical one they acted at times as confidants and were both respected and trusted by the young people:

“The CF nurses are great they’re the ones you can go to about anything I’d trust them with anythin” (female, aged 16).

In spite of adherence to treatment regimes, periods of ill health were seen as par for the course with CF but with the support of their families the young people were able to maintain their positive attitudes even through times of uncertainty. Having CF necessitated reliance on their parents and others for support at times. This was not deemed to be an infringement of their independence as long as it was necessary and that they did not feel overly dependent on others:

“Sometimes ya do need help from people ya know like your parents especially if you’re ill it’s just one of those things with havin CF really” (female, aged 17).

“My girlfriend’s great like really supportive and so are me family but I try not to depend on them too much ya know it’s important to be independent” (male, aged 19).

One participant spoke of how his mum had learnt how to do IV’s at home so he could avoid hospital admissions:

“My parents still do me IV’s at home for me so I don’t have to go into hospital” (male, aged 21).

There was a realisation among the young people that at some stage their health would inevitably begin to deteriorate but comparing themselves with those worse off (both real and imagined) enabled them to appraise their own current situations. These downward comparisons provided justification for the time and effort they invested in keeping themselves well. They served as proof that their health status was at least partly controllable by themselves. It also enabled them to feel grateful about their own situations as compared to others they felt they were in reasonably good health:

“There will be people my age with CF who are a lot worse off but I think a lot of them don’t do their treatments like I do” (female, aged 17).

“My mum’s mate her son has got CF and he’s really ill he looks terrible ya know but I don’t think he looks after himself like I do” (male, aged 19).

“I’m lucky really cos I’ve never been really sick I’ve always been okay and quite well ... I know that some people with CF are a lot worse off and are ill all the time and spend a lot of time in hospital so I am a lot better off than a lot of people with CF but I guess I do try to look after myself and I don’t know if other people do” (female, aged 17).

After comparing himself with those he felt were worse off one participant had come to the conclusion that he must only have mild CF:

“I’ve definitely seen people worse and that’s what makes me think I must only have it mild cos it really doesn’t affect me too much erm, but I have seen other people who are in hospital a lot more than me and they look quite frail and I’m lucky in that respect you know but I also know it’s partly to do with how well I look after myself as well” (male, aged 21).

Knowledge was power for these young people and they actively sought information on their condition and on new treatments from a variety of sources:

“I always ask the staff loads of questions about it like if I’m goin on a new medication then I wanna know what it does an all that” (female, aged 17).

“I try and find stuff out for myself as well ya know like I look on the internet for stuff about new treatments” (female, aged 17).

Knowing that new treatments were being developed and that the life expectancy for those with CF is increasing filled them with hope and optimism for their own adult lives:

“There’s always new treatments being developed ya know so ya never know what’s gonna happen in the future” (female, aged 16).

“You’ve just gotta hope for the best really cos they’re always developing new treatments and every year the life expectancy is goin up” (male, aged 19).

This hope and optimism was tempered with the realism that their CF could not be cured:

“You’ve got to be realistic about it I mean there’s no point thinking oh it’ll be fine they’ll find a cure cos yeah that might happen one day but I know it won’t be in time for me but then there’s still a lot to be positive about cos the life expectancy is always increasing” (female, aged 17).

“This is somethin that’s gonna be with me for the rest of my life ya know but you’ve just gotta make the best of things and get on with life” (male, aged 21).

Keeping well was a way of giving themselves the best chance of a happy future. CF was not perceived to be something that would prevent them from achieving their goals and aspirations but was something that impacted upon decisions about the future:

“There’s nothing to stop people with CF achieving their goals really you’ve just got to stay positive and as long as you’ve got the support of your family then there’s nothing to stop you” (female, aged 17).

“I’ve got plans for the future ya know things I wanna do so I’ve got to keep myself well cos if I just let my health go down the pan then I won’t be able to do anything” (male, aged 19).

Establishing careers, living independently, getting married and having their own families were all felt to be very real possibilities. A normal transition to adulthood was seen as achievable all be it with a little extra support. Accepting support when needed was seen as just a normal part of life for those with CF and something they may need to do increasingly as their health deteriorated:

“Eventually ya know my health will get worse but you just have to deal with it when it happens and it’s not like I’m on me own I’ve got me family to help me” (female, aged 17).

Having never been treated differently by their families because of the CF had enabled the young people to believe they could achieve their goals and encouraged them to make plans for their future:

“My parents never treated me any differently to my sisters not ever really they’ve always just said like whatever you want to do then just go for it don’t let the CF hold ya back” (female, aged 17).

“My mum has always been great ya know just got on with it like to her my CF was just a part of life ya know just part of me” (female, aged 17).

“I don’t think my family treat me any differently because of it they still want me to be independent and go to uni and all that” (female, aged 16).

They anticipated problems along the way but knew they would find ways to overcome them. Barriers could be overcome by maintaining a positive attitude and with the support and encouragement of their families both of which, they were already graced with:

“It’s important to just keep positive you know and see the positive side of things” (male, aged 21).

“I’ve got a good life ya know and I’m happy ... you just have to focus on the good things really” (female, aged 17).

“My family are great I know they’ll always be there when I need them” (female, aged 16).

Planning for the future entailed consideration of their CF and thought was given as to how their goals could be achieved without compromising their health and well-being. For example, those planning to go to university had decided to stay at home were they would have the support of their families and would not have to change CF clinics:

“I am gonna go to uni but I’m gonna stay here and go cos I just think it would be difficult to like move away from me family with me CF and that and it’s better to just be close to them in case I need them ya know I mean it’s gonna be hard anyway just startin something new and meetin new people” (female aged 17).

For some having CF prevented the pursuit of certain career paths but as one participant said this was not the end of the world:

“Well if I didn’t have CF I would of joined the army I think but I couldn’t cos of the CF ... but its fine ya know I’m not bothered there’s other stuff I wanna do so it’s not like the end of the world” (male, aged 19).

They sought to strike a balance between being independent but accepting support when needed. Moving out of the family home was an important step in becoming an adult, but one that was potentially problematic:

"I would like to move out but I wouldn't live on me own like even if it was just sharing a flat with a friend but I wouldn't wanna be on my own cos I just think it would be important to have the support of someone especially if say I wasn't feelin well" (female, aged 17).

Getting married and having children were also envisaged as part of becoming an adult:

"I definitely wanna get married one day that's something me and my girlfriend have already spoken about" (male, aged 21).

"I would like to get married when the time's right" (female, aged 16).

However, there was much uncertainty about whether those with CF can have children:

"I would like to have kids but noone has ever spoken to me about it so I'm not sure whether I can or not" (female, aged 17).

One participant hoped that it would be possible if he had children to ensure that they didn't have CF:

"I'd like to have kids but I've not really had anything said to me about that but I have seen on the news that you can make sure your kids haven't got it and that's important to me I can't be doin with all this you shouldn't be playin god I think it's only right if you can make sure your kids don't have something like CF then you should and there was a thing on the news and the

woman was sayin its right cos kids shouldn't outlive their parents and it's a bit like worse case scenario but I agree with it but I definitely wanna have kids I know I'm young but I have thought about it" (male, aged 21).

Having knowledge about all aspects of their condition was important as it enabled them to maintain a sense of control in their lives. Whilst satisfied with the medical care they received the young people expressed a desire for a greater focus on the social and emotional aspects of living with CF and the implications of having CF on their own personal goals:

"I think they need to give ya more information on stuff like this like careers and families and that and not just the medical stuff" (female, age 17).

"The staff should speak to you about more stuff not just medical just about stuff in general and what's goin on in your life" (male, aged 19).

They also articulated their dissatisfaction with the varying levels of support received by social services as whilst they knew they were entitled to receive certain benefits they had never been given any support to do so:

"The thing with social services is quite bad really it would make things a lot easier if they spoke to ya so ya know what you're entitled to" (male, aged 19)

Part of leading a normal life was to find ways of dealing with the implications of CF. One participant explained how getting help to pay for a car would make a big difference in his life:

"I know that ya can get help payin for a car but I'm not sure how ya do it I asked the social worker ages ago and he said he'd get back to me but he never has ... its annoyin really cos havin a car would just make life so much easier just things like getting to and from uni sometimes when I get in I'm knackered cos I do get tired quite easy so it would help" (male, aged 21).

Having CF would not stop these young people achieving their dreams. Any barriers that having CF may present in achieving these dreams could be counteracted with a positive attitude and a willingness to seek alternatives where necessary.

"It's up to you how ya deal with things and whether you're gonna just stay positive and work through things" (male, aged 19).

"Well there might be barriers in your way cos it can be hard enough to grow up anyway but if you've got somethin like CF it can be even harder but I think it comes down to whether you're an optimist or a pessimist really something is only a barrier if you see it as one that's how I see it" (female, aged 17).

"I know that at some point down the line I might get too ill to work but it's not gonna help to dwell on it you've just gotta stay positive and that's what helps you get through the bad times" (male, aged 21).

Some of the participants noted how they would have to change their lifestyles in the future if their health began to deteriorate:

“If it started getting too difficult to go to work every day then I would just have to do less hours or try and work from home or something like that” (male, aged 21).

“It might get more difficult but you’ve just gotta do you best to work round things” (female, aged 17).

The attitudes of other people towards those with CF were perceived as being out of their control and they anticipated that some people with CF may experience prejudice:

“Some people are just prejudiced towards people if they think they’re different” (female, aged 16).

This was attributed partly to the portrayal of CF within the media. The very little that was in the media about CF was felt to paint a picture of those with CF as being very ill and incapable of having normal lives. This could potentially lead to people feeling sorry for those with CF and thus treating them differently to their healthy peers. This undermined the young people’s own conceptualisations of what living with CF meant to them. They are normal people living their normal lives and therefore, do not need to be pitied and treated as somehow different:

"I just think if there was stuff in the media about it that wasn't so negative then people would see that people with CF are just normal people getting on with their lives ya know and that we don't need to be treated differently or have everyone feelin sorry for us I just think that would help really" (male, aged 19).

Being treated differently and pitied by others would undermine their identity as a normal young person. Therefore, the young people ensured they remained in complete control of whom they disclosed their condition to. One participant had not disclosed her condition to any of her friends. She did not think it necessary to tell friends of her condition as having CF did not hold any implications for her friendships with others. She felt supported by her family and consequently did not need the support of her friends. She could not see any reason why having CF should alter the way her friends treated her but through concern that it might she went to great lengths to conceal her CF:

"I just think they don't really need to know it wouldn't make any difference to them I'd still be me ...I've just always been a bit paranoid that people might treat me differently you know like saying things like oh are you sure you should do that with your CF and that but it shouldn't change anything ... I can get away with not telling anyone so I just think like there's no point in telling anyone... I mean if I didn't have anyone to talk to then I might tell my mates but I don't need to I've got my family and I wouldn't really want to talk to mates about it anyway... Well like if I've ever been off I just tell people I had a bad chest infection ... sometimes when my mates have seen me taking tablets they ask what they're for and I just say I've got a headache or something " (female, aged 17).

For those that had chosen to disclose to some of their friends the decision to do so had been a conscious one and disclosure was never spontaneous. They retained full control of who to tell, what to tell and when to tell. There was fear of a negative response from peers whether this had ever been experienced or not. A negative response was not necessarily a nasty one, what the young people feared most was being treated differently:

"I just want to be treated like everyone else and there's no reason why I shouldn't but you just know there's always gonna be some people who just like change their attitude towards you if they find out ... There's some people who you meet and just know instinctively not to tell them (male, aged 21).

The issue of trust was pertinent in decisions of disclosure and a distinction was drawn between acquaintances and friends. An acquaintance was someone they did not know well enough to tell, someone they did not yet trust. A friend was someone that could be trusted, that is trusted not to tell others, trusted not to react badly and trusted not to treat them differently:

"With an acquaintance I don't know if I can trust them but if I grow to trust them then they are a friend" (female, aged 17).

"You need to know that they are not gonna react badly or like just go and tell everyone" (male, aged 19).

“I have to trust them that they know me enough to know that having CF doesn't affect me in any way that's important towards a friendship” (female, aged 17).

Disclosing to a potential employer was perceived very differently. With friends disclosing was seen as potentially risky unlike with employers where the opposite was true and not disclosing was seen as potentially risky. The young people stressed they would always disclose their condition to a potential employer to avoid any problems later down the line for example, if they needed time off because of the CF.

Disclosing to friends did not hold a specific purpose; the young people did not turn to friends when they wanted to talk about their CF or something relating to it. Rather, it was an act of sharing with their close friends something that is an important part of their lives:

“It's not something that stops me doing stuff you know but it is a big part of me it's a big part of my life and I guess that's why I tell my good friends cos they're a big part of my life too” (female, aged 17).

Unlike friends, partners were a significant source of support, someone that could be confided in about any worries or concerns regarding the CF. Partners were people who provided practical and emotional support but it was important for the young people not to feel reliant upon them. One participant spoke of how her boyfriend wanted to understand and learn more about CF but she did not want him to act as her carer:

“When I told my boyfriend I was like well CF is a part of my life it’s part of who I am and like he was dead good and he really wants to understand about it and know more I just don’t like it if he starts goin on like have you done your nebs and this and that cos it’s like I can look after myself ya know and I don’t want him acting like he’s gotta look after me I don’t need him to do that ...I’ve just started telling him when he does it to stop and he normally does” (female, aged 16).

Friends were not perceived to be a viable source of support, as upon hearing the concerns and worries of those with CF they would then begin to worry themselves. At times it was those with CF providing support to their friends when they had become upset about their condition:

“If they ask me about it I will tell them but I don’t really talk to them about it” (male, aged 19).

“I will talk to them about it sometimes but I try not to go into it too much really cos then they just start worrying about it” (female, aged 16).

“Well a while ago one of my friends had read some stuff about CF on the internet and then she was really upset saying oh my god I didn’t know it was that bad and are you gonna die really young and I just had to say like everyone’s different and I manage my CF and just reassure her a bit really ... she was okay once I explained it” (female, aged 17).

Having an active social life was an important part of being a normal young person. However, having CF sometimes entailed having to make sacrifices:

"I don't really drink cos I just feel guilty if I do cos you know like about me liver like CF affects your liver as well and I just think I'm doin myself no good by drinkin" (female, aged 17).

"As soon as I start feeling unwell then I just make sure I take it easy ya know like if my chest feels bad and my mates ask me to go out I'll just say no cos it's not worth it and you've just gotta think it's not the end of the world there's gonna be other nights out and your health's more important" (male, aged 19).

"You get to know the signs ya know like if I start feelin run down then I just make sure I get loads of rest" (female, aged 16).

Speaking to others with CF was something that the young people felt they might benefit from but again they were not willing to take unnecessary risks with their health:

"I think it would be good to talk to others but you can't cos of cross infection" (female, aged 17).

"I wouldn't want to mix with others ya know just in case I gave them something or they gave me something it's not worth the risk ... it's not that I wouldn't speak to anyone I mean it would be okay if it was by email or phone but I just wouldn't want to in person cos of cross infection" (female, aged 17).

Looking at the bigger picture enabled these young people to see that keeping themselves well had to be their number one priority. There was perceived to be little point in living for the now if it was going to prevent you living your life in the future:

“You could think well I just wanna go out and live life to the full but by not looking after yourself and doing treatments then probably you’ll end up too unwell to do anything anyway and yeah some people might think like what’s the point you can’t cure it but that doesn’t mean you can’t do anything you just have to keep yourself as healthy as possible ” (male, aged 21).

Summary of subgroup 1

For these young people a life with CF was a normal life as it was the only life they had ever known. CF was a stable part of their identities and provided both shape and meaning to their lives. They identified themselves as normal young people and had achieved this through their construction of normality. Being normal holds different meanings and connotations for different people. For these young people being normal including living and dealing with the implications of CF.

Maintaining a sense of control was the primary way in which they coped with their condition. This was achieved through adherence to their prescribed treatment regimes. Despite their condition they perceived their health status to be at least partly within their control and adherence to treatments allowed them to establish and maintain their optimal health status. They

had a high level of trust in health care professionals believing that the advice given to them would always be in their best interests.

The issue of trust was also pertinent in decisions about disclosure to peers and only those deemed trustworthy were told. The young people had to feel sure that disclosure of their condition would not result in others feeling sorry for or pitying them. This was something that could undermine their identity as a normal young person. Therefore the young people ensured they remained in complete control of whom they disclosed to and decisions to disclose were never spontaneous.

Feeling a sense of control over their condition gave these young people hope that they could achieve their aspirations for adult life. They expressed similar hopes and aspirations for adulthood as their healthy peers. Whilst acknowledging that CF would impact upon their future plans they did not anticipate that it would prevent them from achieving their goals. They were realistic about the need to adjust their lifestyles as their condition progressed. They spoke of having good support networks and having been encouraged to be independent by both family members and health care professionals. They strongly believed that having a positive attitude would help them to overcome any potential barriers that having CF may present in the transition to adulthood.

5.6.2 Subgroup 2 - Striking a balance

For these young people living with CF was not a normal life but they tried to lead as normal a life as possible. Doing so involved trying to strike a balance between the CF, its demands and

implications and other areas of importance in their lives, such as, work, education, family, friends and partners. CF was just one of many bases upon which, they constructed their identities. It was an important part of their everyday lives but it did not constitute their primary identity. They defined who they were in the context of their relationships with other people, their membership of different groups and the various social roles they performed. Some of these relationships and roles related directly to the CF and there were times when they felt that CF was the most important thing in their lives:

"Sometimes it can seem like CF is the most important thing especially when you're talking to the doctors and that or when you have to come into hospital" (female, aged 17).

"When you in here (hospital) it kinda takes over ya know all that anybody talks about is the CF and all that ya think about is the CF it's just like everything revolves around it ...I don't mean all the time like I don't spend me whole life like thinking about the CF I just mean when you're in here ya know" (male, aged 20).

One participant spoke of how she was not just a person with CF:

"It's like it's hard to explain really I mean yeah I'm a person with CF but that's not all I am I'm lots of other things too like a student or even just like being a friend so it's not like you know oh you've got CF and that's it" (female, aged 20).

Maintaining a normal life despite their condition required effort on the part of the young people and their ability to do so varied according to their health status. When in good health they were able to achieve a lifestyle similar to that of their healthy peers, to lead a normal life and thus maintain the identity of a normal young person. In times of ill health maintaining a normal identity became difficult if not impossible, as they were required to take on the role of patient.

The role of patient subsumed all other roles and relationships in times of ill health:

“It just depends really like sometimes you feel like I dunno like you can almost forget about the CF and just get on with things but then say if you get sick then the CF kinda takes priority you know and you just have to put everything else on hold” (female, aged 18).

“When you come in hospital ya have to put everything on hold and like that’s all that matters ya know doing your treatments an seeing the doctors and that and then ya have to try and pick up where you left off when ya get out and it’s just hard sometimes” (female, aged 20).

It was important to the young people, to establish similarities between themselves and their healthy peers and to focus on what they could do rather than what they could not do:

“You’ve just gotta try and see the positive really like you can still do everything your mates can really and if you can’t do something say like if you’re in hospital then you’ve just gotta try an I dunno just try not to dwell on it” (female, aged 18).

“There’s no point thinking like I can’t do this and I can’t do that it’s better to just try and focus on the positives cos there’s plenty that I can do ya know sometimes the CF stops me doin stuff like if I’m ill and I can’t go out with me mates but most of the time it’s okay I just get on with it an have like a normal life really” (male, aged 20).

Seeking to achieve a normal life did not equate in any way with a denial of their condition or of the ways in which CF made them different to their peers. It was possible to be both different and normal at the same time but much effort was invested into trying to make the differences not matter. Physical effort was required to fit everything in to their daily lives on top of a time consuming treatment regime and to keep going even when feeling void of energy. Emotional effort was required to try to stay focused on the positives in their lives and not dwell on the negatives:

“Sometimes it’s tiring ya know like sometimes with the CF you just feel like you’ve got no energy and ya could just stay in bed all day but ya can’t you just have to get up and get on with things ya know” (female, aged 18).

“I mean it’s not like you can say oh yeah it doesn’t make a difference to your life at all cos if your honest then yeah it does of course it does but you’ve just gotta find ways round it you know and try not to let it get you down” (female, aged 17).

“I just try and live as normal as possible you know just get on with things and enjoy your life that’s all ya can do and sometimes it’s hard ya know fittin everythin in and tryin to keep yourself well but ya just have to try and get on with it ” (male, aged 20).

“It is gonna be hard when my health gets worse ya know just fitting everything in like jobs and relationships as well as looking after yourself but you’ve just gotta balance it as best as ya can and just go with the flow rather than against the grain cos if your stressing all the time about the future and the CF then you’re just gonna be sad all the time and at the end of the day worryin’s not gonna cure the CF is it?” (female, aged 20).

Striking a balance between the CF and other areas of importance could be difficult and they did not always get it right. Becoming ill was a sure sign that they had not got the balance right:

“My health is a priority but it’s like trying to balance everything out like work, health, university, social life, love life and it can be really hard, sometimes you get it right but sometimes you don’t and you end up in hospital” (female, aged 20).

“Sometimes it’s really hard just tryin to get that balance you know and then like if ya end up ill that’s when ya know you’ve not been looking after yourself properly” (female, aged 18).

Comparing themselves with others with CF (both real and imagined) who were perceived to be worse off helped them to maintain a normal identity, as they believed their lives to be relatively normal in comparison:

“Well some people are really ill with it ya know like in hospital all the time and so I guess for them it would be even harder to just be normal ya know” (female, aged 17).

“I just try and live a normal life you know and I’m quite well really so I can but I think like for people with CF who are really bad then it would just be so hard” (male, aged 20).

Accessing and maintaining a mainstream identity sometimes required the young people to downplay the significance of or sideline their condition. One participant explained how she sometimes neglected her health to a certain extent in order to pursue her goal of obtaining a degree:

“It’s like I’m in uni now and I know that sometimes I don’t look after myself properly say when I’ve got work due in an that cos it just takes up so much time” (female, aged 20).

She would downplay the significance of CF when others suggested she should look after herself better:

“Sometimes me nan and me boyfriend will be like come on slow down and ya need to be looking after yourself a bit better and I’m just like it’s fine and I’ll say I’m fine even if I’m not ya know

even if I'm feelin really run down cos at the end of the day this is really important to me I wanna finish uni and get me degree"

Leading as normal a life as possible was important to these young people but it was something they felt could be jeopardised by others viewing them primarily in terms of their condition. They themselves acknowledged that CF was a fact of their lives but did not want to be perceived by others as an ill person first and foremost:

"I don't want people just looking at me and thinking oh there's that girl who's ill I mean most of the time I'm not ill ya know yeah I've got CF but I'm not always ill" (female, aged 17).

"Like I say you've just gotta try an live a normal life and that's why you don't want people to see ya and just go oh isn't that the guy with CF like that's all that matters" (male, aged 20).

"Sometimes if I'm not feelin well then I won't say anythin ya know to my mum or anyone cos I know that if I do she'll just be worrying about me and askin how I am all the time and she'll probably start with the oh do you think you should be going out and all that" (female, aged 18).

Leading a normal life in spite of their condition was achieved not through denial of their CF in any way but by ensuring that it was not their number one priority:

"The CF is a priority but it's not my number one priority ya know there's other more important things like my family and friends" (female, aged 17).

Whilst it was important to manage their condition it was equally important to ensure that CF did not take over their lives. This was seen most notably in decisions about adherence to prescribed treatment regimes. Whilst adherence to treatments was not necessarily a priority keeping well was. Getting the balance right meant keeping themselves as healthy as possible but still being able to do all of the other important things in their lives, something that was at times a struggle:

“I wouldn't say treatment is a priority but I'd say me health is though, its tryin to balance it with everythin else like uni and social life and love life ... It can be hard you know, really hard sometimes just to get that balance cos it's like you wanna have a life and if you did everything your told to then it's impossible, but on the other hand if you don't look after yourself you'll be too ill to do anything anyway” (female aged 20).

As much as they aspired to lead as normal a life as possible this was not pursued at the expense of their health:

“It's important to have a normal life but there's no point if it's like at the expense of your health cos you can't have a life when you're in hospital can you?” (male, aged 20).

Likewise doing treatments to keep well was not at the expense of other areas of importance in their lives. Striking a balance meant taking considered risks, such as missing treatments occasionally in order to fit everything in:

“I do tend to cut out me physio sometimes time cos I’ve got college and I work and I want a social life too and I feel like that’s just something I need to do so I can fit everything in” (female, aged 18).

Complete adherence was perceived to be an unrealistic goal and something that would have negative implications in other areas of their lives:

“I think if you did everything they tell you to then you wouldn’t have a social life and you’d just basically never be able to leave the house and I do think they can take up too much time” (female, aged 17).

The ability to strike a balance did not come naturally it was a learning process and they had learnt over the years to gauge the level of adherence necessary to keep well:

“You learn ya know what ya need to do and what ya can get away with cos it’s just not possible to do everythin you’re supposed to you’d have no life” (female, aged 18).

“You just have to make choices ya know and sometimes if I’ve got other stuff goin on I will miss stuff but I’m not stupid I wouldn’t just stop doin everythin cos I know I’d just end up in hospital” (male, aged 20).

Planning ahead and seeking alternatives to the more time consuming treatments were important in minimising the impact of the treatment regime:

“Sometimes if I’m goin out and I haven’t got time to do me physio I just use the flutter instead and I know it’s not as good as doin the physio but at the end of the day it’s better than doin nothing” (female, aged 17).

“If you’ve got something on then you just have to plan round it ya know” (female, aged 17).

“If I’m goin out then I just make sure I do my treatments early” (female, aged 17).

Carrying out treatments was something that the young people needed to do for themselves. They had to weigh up the pros and cons and make their own informed decisions. Missing treatments occasionally was not the end of the world but looking at the bigger picture and considering the risks of regular non-adherence provided the motivation to persevere with treatment regimes:

“The way I look at treatments is you’ve gotta do it for yourself and it’s a way I can keep myself healthy but it’s not the end of the world if I miss one, but you have gotta think about things long term and if you just stop then its gonna impact on your whole future” (male, aged 20).

Times of ill health and spells in hospital also served as a good motivator, particularly so when this was perceived to be the consequence of failing to look after oneself. Simply being told by others to carry out their treatments was not enough; they had to learn from their own mistakes:

“Sometimes you don’t get the balance right and you end up ill but you’ve just gotta learn from your mistakes” (female, aged 20).

“When ya come in here (hospital) and ya know it’s cos you’ve not looked after yourself properly it just makes ya think right ya know I’m gonna look after myself a bit better and take things a bit easier” (female, aged 17).

“I did stop (doing treatments) for a while and over time I really did start to see my health deteriorating but I guess experiencing that is a good thing, you learn from that and get to see for yourself why it’s all so important” (male, aged 20).

Being independent was a key factor in leading a normal life but something that proved difficult for these young people who as yet had not taken sole responsibility for their own health care.

Having parents, mums in particular, who were somewhat reluctant to relinquish the control of their health care was perceived to be problematic and resulted in the young people doubting their own capabilities:

“My mum has some of the responsibility, she puts me tablets out and reminds me to do everything and like I’ll say to her that I can do it myself but she doesn’t listen she just does it anyway” (female, aged 17).

“Sometimes my mum goes to extremes if I miss something like she’ll go mad I think to try and scare me into doin everything but she should know I’m not stupid, I might miss something for a day but I wouldn’t go days and days without doin something” (female, aged 17).

“I would like to have complete responsibility really it’s just a bit worrying like what would happen if there was no one there to remind me to like take me tablets ... me mum always says if you ever move out I’ll have to phone ya ten times a day to make sure ya don’t forget to do eveythin” (female, aged 17).

For those who had not yet made the transition to adult care not having sole responsibility for their health care was a cause for concern. Paediatric staff had tried to prepare them for the transition but their parent’s reluctance to relinquish control made this difficult:

“I just wish they’d let me do things for myself ya know instead of tryin to do everythin like my mum would still come in with the doctor if she could but they won’t let her anymore she’s only allowed to come in at the end but even then she’ll be like did she tell you she’s been coughin and have ya checked this and that ya know like she just thinks I can’t talk for myself and like the

other week the doctor wanted to put me on a new neb and I didn't want to cos I was doin fine with the one I already had so I was like no I'd rather not and me mum was just like don't listen to her she will do it" (female, aged 17).

Making the transition to adult care had proven to be a positive move for those that had made it. Staff in adult clinics were perceived to be much more understanding about the impact of treatment regimes and willing to help the young people find practical solutions to their treatment related problems:

"Before I moved over here to the adult clinic my parents were always on my back about treatments asking what I'd done and trying to tell me when to do things, but like when you come here you do everything on your own, that's what they expect erm, so they didn't have much choice really they just had to let me get on with it" (male, aged 20).

"I think at the children's hospital they were just tryin to say this comes before your life but coming over here they realise that if I've got work and other things like that then I do have other responsibilities than my health and they do try and come up with ways to get round it" (male, aged 20).

"It's like here (in the adult clinic) they do understand that I've got other commitments but they didn't at the children's hospital you would just get a lecture" (male, aged 20).

"They do try to be practical here (in the adult clinic) like I spoke to the physio and told her that I was struggling to fit everythin in and she gave me the pep mask to use when I can't fit the physio in, they do realise you can't always do everythin and I think as long as your honest with them then they will try and help you" (female, aged 18).

However, the transition to adult care had proven to be particularly distressing for one participant who had made the transition from a peripheral paediatric CF clinic. Prior to the transition she had been given very little information on CF in general. Learning about the implications of having CF in adult life had come as shock:

"It was a real shock comin here and learnin how much the children's clinic had kept from me I just had no idea how things can be and how bad things can get and then you come here and it's much more forceful like if ya don't do your treatment this might happen and I didn't know about any of the problems that ya can get with CF like diabetes or liver problems ... in the children's clinic it was just about dealing with the here and now" (female, aged 18).

The depression that had followed the shock of learning these implications had resulted in a phase of complete non-adherence:

"It was really really difficult and it made me depressed and it was like havin to leave behind your childhood but then adulthood just sounded so scary ... when I was in the children's hospital

I felt like the CF wasn't a really big deal it was just like say having an extra finger or something and then I came here and I felt like I was the CF and the CF was the most important thing ... the worst thing was finding out about the life expectancy cos like I didn't know that ... I just got really down and was refusing to do any treatment for a few months and then I ended up really sick."

Although she was now coming to terms with the information given to her adequate preparation for the move could have prevented the distress and shock experienced by this young person:

"I am coming to terms with it now I just wish I had been prepared for it."

Overprotective behaviour from parents not only impacted upon the transition to adult care but also made it generally more difficult for the young people to establish their own independence:

"My mum and dad just try to wrap me in cotton wool like they wanna to do everythin for me and they don't want me to do anything they drive me mad with it sometimes cos it's like how am I supposed to be independent?" (male, aged 20).

"That's the hardest thing with CF ya know being independent especially at this age I mean I'm an adult now but I've still got people fussin over me" (female, aged 20).

They expressed many aspirations for their adult lives such as living independently, establishing careers, getting married and possibly having children but were doubtful of the extent to which their parents would support and encourage them to achieve their goals:

"I don't think me parents would be too happy about me movin out I do want to like but I reckon they'd try and talk me out of it cos they'd just be thinking I wouldn't look after myself ... the thing is though I would look after myself I'm not stupid and I'm never gonna be independent if I carry on livin with them all me life" (female, aged 18).

These young people also had their own personal concerns and worries to contend with. The progressive nature of their condition gave them much cause for concern. Fears of declining health in years to come placed somewhat of a black cloud over their aspirations for adult life:

"I would really like to move out at some point but then ya just don't know what's gonna happen with the CF so it's hard to make plans ya know" (female, aged 17).

"There's loads of things I wanna do in the future but sometimes ya just worry ya know like what's gonna happen when your health gets worse and ya just think will I get to do everythin that I wanna do" (female, aged 20).

The young people acknowledged that having CF would impact upon and make their transition to adulthood more difficult to achieve and that their subsequent adult lives would differ in many ways to the lives of their healthy peers. However, they were still determined to lead as normal a life as possible and to at the very least try and achieve their goals:

"I definitely want a career that's why I've gone to uni but I do worry about it cos you've got to be able to have the energy to be able to get out there and go to interviews and chase a career and I just think well I hope it doesn't get to the point where I haven't got the energy and I haven't got like the health I need but ya know I'm not just gonna stop cos that's the whole reason for goin to uni but you do worry about it cos some people might not get their careers sorted til they're like thirty ... but I won't let it stop me tryin I know there will be problems later on but you've just gotta do your best" (female, aged 20).

"CF does make things difficult of course it does as much as ya try not to think about it ya know in your heart of hearts that there's gonna be things that ya wanna do but when the time comes ya might not be able to like I dunno erm, like gettin a career but then what's the point if you're not gonna try? What kinda life would that be if ya didn't try an do anything just in case ya couldn't?" (male, aged 20).

Living with CF, a condition with a limited life expectancy, created a sense of pressure to achieve the markers of adulthood earlier than was the norm:

"It does affect ya growing up cos like I know it sounds morbid but it's like ya know you're goin into adulthood with a reduced amount of time and it just kinda puts pressure on ya to do things and think about things that people your age wouldn't normally be thinking about yet" (male, aged 20).

"Sometimes ya just feel like I'll have to do everythin sooner ya know just cos ya don't know how long ya gonna feel well like if I wanted to have kids I couldn't like wait till I was thirty like most people can if I was gonna have kids then it would probably have to be I dunno, in the next few years I guess" (female, aged 17).

In addition to their concerns about the progression of their condition what made the transition to adulthood more difficult was the perceived lack of both practical and emotional support. Whilst they recalled relatively unproblematic experiences of school those that had gone on to further education expressed dissatisfaction with the level of support they had received:

"It's been really hard in college cos like at first my tutor was like oh if you need anything just ask but she's been rubbish and if I go to her about something she never gets back to me and say like in school if I was off they would get work together for me but at college they don't and I just have to come back to it all and it's not very organised, they don't give me any support at all really and I do say stuff but the tutor will just be like well there is another twenty people in the class and my mum has even phoned and spoke to her when I've been upset about it but it doesn't make any difference" (female, aged 17).

“In uni I just feel like it’s not integrated enough with like contact with me tutor and stuff you don’t feel like there’s any support there really” (female, aged 20).

Another participant had felt unsupported in the workplace and had consequently given up his job:

“When I had to take time off they were really unsupportive and like I’d told them from the start that I had CF but they treated me really badly and one time I was admitted to hospital so I had like a doctor’s note but they said they were givin me a warnin for being off so I left anyway” (male, aged 20).

Other potential sources of practical support had not been easily accessible, social services in particular:

“I’ve never even spoken to a social worker never even met one” (male, aged 20).

“I did speak to the social worker in the hospital and they’re supposed to be helping me fill out some forms but it’s been ages now and they’ve not got back to me” (female, aged 18).

They expressed a desire for those professionals who played a role within their lives to provide more information on and support for making the transition to adulthood, particularly with issues

such as having children. They felt too much emphasis was placed on purely medical issues at the expense of social and emotional issues:

“I just think they should talk to ya about other stuff like getting jobs or moving out ya know not just the medical stuff” (female, aged 17).

“They should help ya with this kinda stuff ya know like when you’re worried about jobs or movin out but they don’t it’s all just about treatment” (female, aged 17).

“I’d like to get married at some point but I’m not sure about kids I don’t know whether I’d be able to have kids noone’s ever said anything about it” (male, aged 20).

“They definitely should give you more information on things like having kids” (female, aged 17).

Maintaining a positive attitude and having good support networks were seen as crucial in dealing with their condition and its implications. Yet these young people spoke of the loneliness and isolation they sometimes felt in trying to deal with their condition. In spite of efforts to remain positive about their lives and futures there were times when the burden of living with CF became overwhelming. The young people would try and overcome these feelings by dealing with problems as they occurred rather than dwelling on what might happen but this was not easy and at times seemed impossible:

“Sometimes you’ve just gotta try and forget about it ya know I erm, I don’t mean like stop doin you’re treatments or anything like that just like try and enjoy life now and not worry about what’s gonna happen in the future” (female, aged 17).

“It can be really overwhelming when ya start thinking about the future and what’s gonna happen with the CF and it’s like ya just have to try not to think about it too much ... but to be honest with ya that’s easier said than done sometimes I’d be lying if I said there weren’t like times when it really got me down” (female, aged 18).

During these times when they felt at their lowest they struggled to find someone they could turn to and confide in. CF nurse specialists were considered to be a potential source of emotional support but opportunities to speak with them were limited:

“The nurses are lovely and I can talk to them but you don’t really see them on your own there’s always other people about so it’s not like your gonna talk about anything personal with them” (female, aged 18).

They were reluctant to go to family members with concern’s as they did not like to burden them and felt that confiding in them may only serve to heighten their over protective behaviour:

“Sometimes it gets on top of ya and it’s like ya can feel really isolated and it makes ya feel like you’re the only person in the world who feels like that ... I always feel like I don’t wanna burden

anyone (family) though and so a lot of things I don't speak about and just get on with it" (female, aged 20).

"It's really important to have people who ya can talk to about it ... I just tend to deal with things myself though" (male, aged 20).

"I just feel like if I tell them I'm worried about something then they'll be even worse sometimes I just feel like they smother me and don't want me to do anything for myself" (female, aged 17).

A solution to this was to speak with someone who did not know them personally but opportunities to do so were scarce:

"I just think there should be more emotional support and maybe counselling from someone who doesn't know you personally and I don't mean for if your depressed I mean just being able to talk about everyday things rather than purely medical stuff and just anything about the CF you should be able to talk about and I think if there was just someone you knew you could talk to cos just like havin a chat can help and I know they couldn't talk about other patients but even just to give you peace of mind that there are other people who feel the same" (female, aged 20).

"I wish there was someone I could talk to ya know someone who didn't know me so I could just say whatever I wanted without worryin what they thought" (female, aged 17).

Feeling that those close to them did not understand what they were going through was at times very isolating. Speaking with others with CF was seen as a way to overcome these feelings of isolation but they had little or no opportunity to do so due to the risk of cross infection:

"I would really like to talk to others with CF just cos they'd understand what it's like and sometimes ya just feel like ya goin crackers cos no-one understands what it's like like say I said to me mates oh I'm worried that I won't be able to have kids they'd just be like you're only 17 what are ya worryin about that for, they'd just think I was being stupid but like someone with CF would understand but ya just don't get the chance to talk to anyone cos of cross infection they don't let ya mix with others in hospital" (female, aged 17).

One participant felt that there was an unnecessary stigma surrounding the issue of mixing with others that had been created by hospital staff:

"I know it's in our interests but the staff here make such a big deal of it there's like a real stigma about it and I just think well if there was that much more we could catch off each other would they really put us on the same ward" (female, aged 20).

Close friends and partners were people that could be confided in about worries relating to CF.

The young people did not anticipate that their friends could understand what they were going through but appreciated being able to get things off their chest:

"It's nice that your mates know cos sometimes you need someone to talk to who's not like really close to it all like your family are" (female, aged 20).

"I can talk to me mates about it they're dead good about it and just listen to me even though they probably don't know what I'm talking about most of the time" (female, aged 17).

"I know they can't understand what it's like to have CF an that but sometimes it's just good to get things off your chest" (male, aged 20).

Joking with close friends about their CF also helped to lighten the mood:

"Sometimes if I'm with me close mates and say if I have a coughin fit we just laugh about it" (female, aged 17).

"Yeah like me close mates who know they make little jokes about it and we have a laugh about it sometimes" (female, aged 17).

It was only those people considered to be close friends that the young people disclosed their condition to and they retained control over whom to tell, what to tell and when to tell:

"You just have to think it through first you know like if there is someone you wanna tell then you need to think about how to tell them and not just blurt it out" (female, aged 17).

“At the end of the day it’s a really personal thing so why would you just go round telling anybody and everybody” (female, aged 17).

Friends that they had not disclosed their condition to provided a much needed source of distraction during difficult times:

“If I’m feelin down about stuff then I just try and do stuff to make me forget about it like sometimes I will hang out with me mates who don’t even know I’ve got it cos then ya can just forget about it and noone’s askin about it” (female, aged 20).

Fear of a negative reaction and being pitied by others prevented them from disclosing to those considered only friends and not close friends:

“Some people would just be idiots about it if you told them like saying stupid stuff like can I catch it?” (male, aged 20).

“It’s just hard enough you know you do your best to cope with the CF and have like a normal life and the last thing you want is people treating you different like being horrible or feeling dead sorry for you ... you just wanna be able to get on with things” (female, aged 20).

The low visibility of CF meant it was relatively easy to conceal but at times the young people found themselves in situations where they had to take extreme measures to conceal their CF from those they did not want to know:

“Well the thing is you can’t really see it whereas with some people you can see their illness but if you lined me up with other people and said which one has got CF then you wouldn’t know”
(female, aged 17).

“I gave some people from college a lift and they saw me disabled badge and were like why have you got that and like it was terrible cos I had to say oh I lied to get it so now they think I’m committing benefit fraud” *(female, aged 20).*

The need to conceal their condition arose partially through the belief that there was little awareness of CF within the general public. The young people worried that most people would only know about CF if they had seen something about it in the media. Media portrayals of CF were deemed to be inaccurate and overly negative. Thus they anticipated that those with any awareness of CF would hold misconceptions about the condition, believing that those who have CF are permanently ill and incapable of leading a normal life:

“Erm, they always seem to focus on the limited life expectancy and that side of it and they don’t really show people my age who like even though they’ve got CF they’ve still got a life and I think they should show that but they just show people who are really ill and on oxygen all the time”
(male, aged 20).

“Stuff in the media just shows it at its worst and then people assume you’re really ill and like housebound or something or that if your okay it must just be cos your goin through a good patch” (female, aged 17).

Such misconceptions could not only undermine their efforts to lead a normal life but also create stigma around their condition. Consequently, the young people were wary of disclosing to those who may be in a position to discriminate against them, for example potential employers:

“It’s hard really cos I’d be worryin about telling them in case they wouldn’t give me the job cos of the CF but then if ya don’t tell them what are ya gonna do if ya need time off?” (female, aged 17).

“I don’t think I’d tell them until I’d been offered a job that way they wouldn’t be able to just not give me the job cos of the CF” (female, aged 18).

A more positive portrayal of people who live with CF would not only have the potential to allay any misconceptions about the condition but it would also provide the young people with positive role models, something they felt would give them hope for their own futures and encouragement to achieve their aspirations for adult life:

“I think there are people out there who are quite negative towards people with CF say like employers they would just assume that your gonna need loads of time off and you’ll always be ill but I think a lot of it is down to them just not knowing much about what it is and people just need

to be better informed about it and see for themselves that you can still have a life and do normal things like getting a job” (female, aged 17).

“You need a role model you don’t want to see just the bad side of it ... you need to show people that people with CF go out, they work, they have normal lives, they can have families, they’re active and they don’t spend all their lives in hospital ... They (the media) need to show that side of it.” (female, aged 17).

“It’s like if you could see for yourself other people with CF going out and achieving their goals then that would encourage you and just make you think well if they’ve done it I can do it to” (female, aged 20).

Summary of subgroup 2

For these young people living with CF was not a normal life but they tried to lead as normal a life as possible. The primary way of doing this was to strike a balance between the CF and other areas of importance in their lives. CF was just one of the many bases upon which, they constructed their identities. It was an important part of their everyday lives but did not constitute their primary identity.

Maintaining a normal life in spite of their condition required both physical and emotional effort as they tried to make the differences between themselves and their peers not matter. Keeping well and managing their condition was a priority but they felt it was important that the CF did not take over their lives. They were willing to take considered risks when it came to treatment such as, missing treatments occasionally in order to fit everything in.

Asserting their independence was at times a struggle particularly as they felt their parents were somewhat over protective of them because of their condition. They expressed many hopes and aspirations for their futures but the progressive nature of their condition gave them much cause for concern. Living with a condition that has a limited life expectancy created a sense of pressure to achieve the markers of adulthood earlier than was the norm. In spite of efforts to maintain a positive attitude there were times when the burden of living with CF became overwhelming. This was compounded by the lack of both practical and emotional support they received and consequently these young people felt both isolated and lonely at times.

The young people expressed a desire for greater support in dealing with their condition. They felt it would be particularly helpful if they were able to speak with someone who did not know them on a personal level as they were reluctant to burden those close to them with their worries. They also felt a more positive portrayal of young people with CF in the media would provide them with positive role models, something they did not currently have. This would give them hope for their own futures and encouragement to achieve their aspirations for adult life.

5.6.3 Subgroup 3 - I want to be normal

For these young people having CF is not normal. It is something they fear could prevent them from leading a normal life and being perceived as a normal person. They actively rejected CF in the construction of their identities striving instead to achieve a mainstream identity. They did not describe themselves as normal, they stated that they wanted to be normal and as such their primary aim in life was to achieve a lifestyle similar to that of individuals of their social status, who do not have CF:

“I just wanna be normal ya know be like everyone else my age just a normal teenage lad and just do everything that a normal teenage lad does ya know go out for a few drinks, play footie and all that” (male, aged 17).

Their primary way of coping with CF was to not let it be a priority in their lives. They refused to let their condition prevent them having a lifestyle comparable to that of their healthy peers. They achieved this by distancing themselves from their condition and rejecting anything that served as a reminder of it:

“I just don’t think about it I don’t wanna think about it cos what’s the point ya can’t change it” (male, aged 18).

"Ya don't wanna be reminded of it I think it's better just to forget about it and not think about it really or you'd just be depressed all the time" (female, aged 18).

Treatments were seen as a potential daily reminder of their condition, something that might prevent them from leading the lives they wanted to and something that could set them apart from their peers. The young people perceived that they had the choice to either adhere to their treatment regimes or live a normal life, with very little middle ground. Consequently, they reported being non-adherent on a regular basis:

"At the end of the day it's your choice yeah you could do the treatments but that means having no life cos it just takes over and it takes so much time and at the end of the day I'd rather have a life ... I just wanna be normal you know and be able to do what I want like go out with mates and that ... There's no way you can do what you're expected to and still have a normal life, you just can't" (female, aged 18).

"I'll put it to ya straight I don't do it ... I've got more important stuff to do you know just normal teenage lad stuff" (male, aged 17).

"I don't do it I don't care there's no way you can have a normal life if ya do all that no way" (male, aged 17).

Treatment was not a current priority for these young people. They all described themselves as being in reasonable health and felt there was no direct association between non-adherence and

deterioration of health. Particular reference was made to physiotherapy as the young people perceived this to be the most ineffective of all their treatments:

"I don't think my health has ever suffered cos of me not doin treatments it's not like I feel ill if I don't do them" (female, aged 17).

"I'd say I've done me physio say ten times since 2002 truthfully so that's an awful lot of times it hasn't been done cos you're meant to do it twice a day er, but each year you get an annual assessment and this year everythin come back normal on it so for them to say like if you don't do your treatment your chest gets bad well" (male, aged 17).

"I hate physio I never do it cos it takes ages and it doesn't even do anything so there's no point" (female, aged 18)

"I never do physio there's no point it's just like an hour of my life wasted everyday and people might say oh its only an hour and it just like well it's easy to say that" (male, aged 17).

They held the belief that all young people with CF are non-adherent to some extent:

"I think you could probably figure out yourself none of us do our treatments ... Some people might say to the staff that they do everythin but they're just lying" (male, aged 17).

Comparing themselves to others with CF whom they perceived to be worse off provided justification for their non-adherence, as compared to others they felt they were in reasonably good health:

“There’s some people who are in here (hospital) all the time you know and I bet they do their treatments more than me but they still get sick all the time so it just shows ya really it doesn’t make much difference” (male, aged 17).

“Sometimes the staff here will have a go like ya know ya need to look after yourself better but at the end of the day there’s people in here a lot worse off than me so I think I’m doin okay ya know” (female, aged 18).

Fitting in, feeling part of their peer group, acceptance by their peers and being perceived as normal were all of primary importance. Carrying out treatments posed a risk to all of these things. Consequently all aspects of carrying out treatments were avoided in the presence of peers and social activities with peers were always given precedence. This enabled the young people to minimise any differences between themselves and their peers and thus reduce the potential for stigmatisation:

“My mates are my priority really like and if you’d rather be doin something other than treatment then you should just do it and just enjoy your youth, that’s what I’m doin” (male, aged 17).

“Doing treatments is the worst thing about CF it’s definitely the thing that makes you feel different to everyone else cos it’s not like anybody else has to do physio twice a day and nebs and take shit loads of tablets everytime they eat and that’s why CF’s don’t do it you know we just wanna have a normal life too” (male, aged 17).

“Well you’re hardly gonna sit there and get your tablets out in front of your mates like I’m supposed to take fifty a day, people would think you were a right freak if they saw how many you had to take and there’s no way you would want anyone to see you havin say physio, that would just be embarrassing when you’re coughing up a load of phlegm and even if they were in a different room you could still hear it” (female, aged 18).

The course of CF was perceived to be both unpredictable and uncontrollable. Thus participants felt they had little or no control over their own health status. Adhering to treatments did not in any way serve to increase the participants’ sense of control over their condition:

“I don’t think it makes any difference whether you do your treatments or not like I don’t do most of what I’m supposed to do and it’s not like I’m in hospital all the time, if you’re gonna get sick then you’re gonna get sick there’s nothing you can do about it” (female, aged 17).

“It’s not like I can control what happens I mean it’s the CF that controls it I guess erm, cos at the end of the day if it’s gonna take a turn for the worse then there’s nothing ya can do about it” (male, aged 17).

They felt it inevitable that the final outcome of having CF would be a premature death and therefore felt they should make the most of their time now. Treatments were perceived to be something that could impinge on what time they had left:

“I know personally that say twenty years down the line I will either be dead or very ill and you know I could spend all this time now doin treatments but at the end of the day it might not make any difference and you could be missin out on doin just normal teenage stuff like hanging out with mates playing footie and goin the pub and it could be for nothin it’s still gonna kill ya, you’ve just gotta enjoy your life now you know ” (male, aged 17).

“I just think well I might only have another ten years so you’ve just gotta try and make the most of it whatever ya do it’s gonna kill ya in the end” (female, aged 18).

“Maybe I will pay for it in the future I don’t know but at the end of the day you’re gonna get sick whether you do it or not you can’t change the fact that you’ve got it so why not just enjoy life while you can, that’s what I think anyway” (female, aged 18).

They did acknowledge that their non-adherence now might yield consequences for them in years to come. However, non-adherence in the short term was not perceived to hold any immediate physical consequences and this enabled them to postpone dealing with their CF and ignore the advice of both their families and health care professionals. For now the potential consequences of non-adherence did not seem real but the young people acknowledged that this may change in the future:

"If I do start to get chesty I'll probably start doin some more treatment" (male, aged 17).

"I mean I know me health is gonna get worse at some point so maybe I will have to start helping meself soon, just have to see what happens and I dunno maybe it'll change once I go over to the adult clinic and like see people dying over there" (male, aged 17).

One young male spoke of being fully adherent to his diabetes treatments but regularly non-adherent to his CF treatments.

"I always take insulin for me diabetes I never miss that it's just the stuff for the CF I miss" (male, aged 17).

He attributed his adherence to diabetes treatment to a fear of the physical consequences to his health that non-adherence posed. These consequences, unlike the consequences of non-adherence to CF treatments, he felt would have a direct impact on his life here and now and prevent him from doing things important to him. In addition he noted treatment for diabetes is much less complex and time consuming.

"The diabetes is more important cause I could go blind or lose me fingers and then I wouldn't be able to play the guitar... and it's just easier cos all I have to do is take insulin twice a day" (male, aged 17).

Their non-adherence was a source of conflict with both parents and members of staff who regularly tried to persuade them to adhere to their treatment regime. The young people paid little regard to this believing that ultimately they had responsibility for their health care. This responsibility meant that it was their choice whether to adhere to their treatment regime and much of the time they chose not to. Having this choice allowed them to feel an element of control over their lives, they could not control the CF or its progression but they could control how they lived their lives in the here and now:

“There’s nothing I can do about havin CF nothing at all but it’s up to me how I live me life it’s my choice and I don’t care how much people nag me to do me treatments at the end of the day it’s my choice” (male, aged 18).

“When I was little they used to make me but they can’t do that now it’s my responsibility so it’s my choice whether I do it and I don’t care what anyone else says about it it’s not their life” (male, aged 17).

As far as the young people were concerned it was not possible for anyone without CF, no matter who they were, to understand what it means to live with the condition:

“The staff just don’t understand they’re just like you’ve gotta do it but they’re not the ones expected to have no life are they” (male, aged 18).

"It's hard to explain to someone who hasn't got CF you can't understand if you haven't got it"
(female, aged 18).

"Your parents just listen to what the hospital says so like then they get on your back too about doin your treatments and they just don't understand what ya would have to sacrifice" *(female, aged 17).*

Hospitals were the places that these young people felt at their most vulnerable but also most supported. Periods of ill health brought home the harsh reality of having CF, something the young people did their best to avoid thinking about. However, it also provided them with the opportunity to speak to others with CF all be it against the advice of hospital staff:

"I do talk to other CF'ers in here like cos they're the only ones who can understand and like the staff will be like we understand it's hard and it's like yeah right how could you understand you haven't got it" *(female, aged 18).*

"It's good to just chat to people who understand what it's like an like we're not supposed to like mix cos of cross infection an that but I don't care" *(male, aged 17).*

In the hospital setting they could acknowledge their condition without the fear that it would set them apart from others. They expressed the belief that most young with CF had a similar attitude towards the condition as themselves:

"I talk to others with CF when I come in here (hospital) like and they're just the same ya know all CF'ers are we just wanna have a normal life" (male, aged 18)

Those that had not made the transition to adult health care were concerned that staff in the adult clinic would be stricter on the matter of mixing and when it came to treatments. They were therefore reluctant to make this transition:

"I don't wanna go I think they'll be like be dead strict about ya not mixin with others ya know cos of cross infection (male, aged 17).

"I think they'll just be on your back an like telling ya off all the time for not doin your treatments" (male, aged 17).

All of these young people had attended or were still attending the same regional children's hospital and thought highly of the staff there. The transition to adulthood was a difficult time and they did not want to add to this by moving to a new hospital:

"I like it here ya know I know everyone and they all know me it's just stupid really they should just let ya stay I mean at this age you've got enough goin on without havin to worry about that as well" (male, aged 17).

Attempts by staff to allay their concerns and prepare them for the move had fallen on deaf ears:

"They have said stuff like but to be honest I've not paid much attention cos I don't wanna go really I'd rather just stay here" (male, aged 17).

Those that had already made the transition actually preferred the adult clinic as they felt the staff there were much more accepting of their decisions about treatment:

"They don't go on at ya as much here they know it's your decision at the end of the day" (female, aged 18).

"They just go well it's you who'll regret it but they don't go on about it that much" (male, aged 18).

For these young people living for the now meant living their lives in a similar manner to their peers. However, living for the now also created a striking difference between these young people and their healthy peers. Most young people their age would be looking towards the future, beginning to think about their goals and aspirations for adult life and setting about achieving them. In contrast these young people anticipated unsettled futures. They did express some aspirations for their adult lives but were reluctant to talk of any future plans or hopes. Believing the course of their condition to be highly unpredictable and likely to change at the drop of a hat resulted in any future plans being held in abeyance:

"To be honest with ya it's hard cos like I do wanna move out and maybe get married one day but then I dunno its hard to say at this time what'll happen cos like with CF it can turn so quick like say I can be here talking to you and tomorrow I could be in intensive care" (male, aged 17).

"You just don't know what's gonna happen with your health really ya know it's gonna get worse the older ya get so ya don't know what you'll be like in a few years and what you'll be able to do" (female, aged 18).

Whatever the future might hold they anticipated that due to deteriorating health their lives would be somehow worse in the future than they were at present. This reinforced their desire to live for the day and enjoy their youth:

"There's things I'd like to do but ya never know when things might turn so there's no point thinking about it really just enjoy life while ya can" (female, aged 18).

"You've just gotta live for the day and enjoy your youth there's no point worryin about it like oh if I don't do this what'll happen an all that there's no point thinking like that ya know just enjoy it while ya still can" (male, aged 17).

The way they perceived they lived their lives did not appear to match up to the reality of them. They expressed the view that CF would not prevent them from doing anything but when discussing their futures they identified many ways in which having CF may do just that:

"If I wanna do something then I'll just do it there's no way I'm gonna let the CF stop me"

(female, aged 18).

"I would like to move out but I just can't see it happenin not anytime soon anyway like it would just be really hard livin on your own with CF cos like if you got sick you wouldn't wanna be in a house on your own" (male, aged 18).

"I'd like to get married at some point but then it depends on me health cos like if it's bad then I wouldn't want someone bein with me and havin to be like me carer rather than me husband ya know I wouldn't want that" (female, aged 18).

Their views on having children also revealed the extent to which they felt CF had impacted upon their lives. Having children was not considered an option as they would not want their children to go through what they had been through:

"I really don't wanna have kids to be honest cos they might have CF and I wouldn't want them to go through what I go through" (male, aged 17).

"I already know I don't want kids I wouldn't have them in case I gave them CF cos I mean I hate it I hate CF so I why would I wanna put me kids through it?" (female, aged 18).

None of these young people expressed any plans to enter into further education after sixth form. Little thought had been given to the possibility of establishing a career as there was perceived to be little point in doing so. One participant felt that it would be a waste of her time to try and establish a career:

"I'm just working in MacDonal'd's at the moment me mum keeps goin what are ya gonna do? And I'm just like I don't know cos like there's no point like goin to uni or anything like that cos by the time you've done all that and got yourself a career you'll probably too sick to work"
(female, aged 18).

In spite of their many concerns and anxieties about the implications that CF may have in their adult lives this was not something that they chose to discuss with anyone. Problems were by no means shared, perhaps because of a reluctance to admit that having CF did impact upon their lives:

"I don't need any help I can sort out me own problems" (male, aged 17).

"To be honest with ya if I've ever had any problems then I just deal with it myself" (female, aged 18).

"If anyone said anything bad to me about it I'd just batter them I don't need anyone else sortin out me problems" (male, aged 17).

"I don't want people helping me out just cos I've got CF I don't need it I just get on with it myself you know I just wanna be normal" (male, aged 18).

"I have been offered like counselling but I'd rather just leave it all if I've got a problem then I'd rather just sort it myself I don't wanna start goin to people to sort stuff for me" (male, aged 18).

Family members and health care professionals were believed to place too much emphasis on the CF when in fact the young people were doing their best to avoid thinking about it:

"It's just like all anyone wants to go on about is the CF and treatments and I can't be doin with it I just wanna forget about it and get on with me life" (male, aged 17).

"I don't wanna know everythin about it ya know all the bad things that can happen you'd just be worryin all the time" (male, aged 18).

Receiving practical support, like carrying out treatments, had the potential to make them feel or look somehow different to their healthy peers. Consequently offers of practical support had been refused, particularly within the school setting:

"I just said no to anything they offered me I didn't need it" (male, aged 18).

"I didn't want any extra help I didn't wanna be treated differently to everyone else that's just like askin to get bullied that an it's not like I've got special needs" (female, aged 18).

Leading a normal life was only possible if the young people were perceived by others as normal and thus not treated differently to their healthy peers. It was vital to these young people that others did not look upon them with pity or sympathy as this would undermine their identity as a normal young person:

"I don't want people feeling sorry for me it just makes me mad really I don't need it I don't need their sympathy" (male, aged 17).

"Oh I hate it ya know when people start feelin sorry for ya cos then they like start treatin ya different like ya not normal saying stupid stuff like oh do you need to sit down ... it pisses me off" (female, aged 18).

"I just want a normal life I don't need people to feel sorry for me cos then they treat ya different like ya not normal and can't do normal things like your mates and that" (male, aged 18).

The portrayal of CF within the media gave these young people cause for concern as what little there was in the media tended to emphasise what they felt was a worst case scenario. This is something that might evoke sympathy for those with CF:

“It makes me angry and I get upset when I read stories about CF in the papers cos it just makes out like people with CF can’t have a normal life ya know it just shows the worst case scenario and it’s not like that’s gonna teach people about CF and what it is it’s just gonna make people feel sorry ya” (female, aged 18).

Whilst it was deemed inappropriate and unnecessary for others to feel sorry for them there were times that the young people felt sorry for themselves that they had this condition. One participant had spoken about how he did not want others to feel sorry for him but then went on to say they also should not think him lucky in anyway:

“Some people say oh you’re lucky you know like cos I’ve got me car but why am I lucky? how are ya lucky? and it’s like well but you’re gonna live till your seventy, eighty and I’m not so how’s that lucky” (male, aged 17).

For a number of reasons it did not strike me that these young people were in complete denial of their condition it seemed more so that the way in which they coped with their condition was to avoid thinking about it. Given the emphasis placed on leading a normal life and the fear expressed by these young people about being treated as somehow different to their peers I was

somewhat surprised that they did not attempt to 'pass as normal'. Particularly so given the relatively low visibility of CF in comparison with other impairments.

They identified certain benefits of having CF something that one might not expect someone in denial of their condition to do:

"Well one good thing is that I can use it to get out of P.E." (male, aged 17).

"It might sound mad but it does have its advantages like me havin me car I've only got that cos of the CF so that's a benefit really" (male, aged 17).

Of all the participants these young people had the most contact with social services and had received help from social workers to apply for various benefits they were entitled to:

"The social worker helped me sort out me disability living allowance" (female, aged 18).

"Yeah I get money towards me car I can't remember what it's called the social worker told me about it and helped me do the forms" (male, aged 17).

"It's great some of the things ya can get I guess havin CF does have some perks (laughs) like I can get help with payin for drivin lessons and then I think once I've passed I can get money towards payin for a car (male, aged 17).

Even more surprisingly the young people did not attempt to conceal their condition from their peers and disclosure was more of a spontaneous act rather than a conscious decision. As with their condition in general, they did not perceive that others knowing about their condition was something they had great control over. They did not decide to tell or not to tell it was more a case of if it happens it happens. If it came up in conversation they would disclose their condition rather than attempt to conceal it:

“Well when people say why were you off or why are you coughing I’m not gonna lie I just tell them” (female, aged 18).

“It’s like in school you’ve got to take your tablets so people are bound to ask what they’re for so I just tell them I’m not bothered” (male, aged 17).

How well they knew a person was not an issue and they all stated that the majority if not all of their peers knew they had CF either because they had told them or someone else had:

“Everyone in my year knows I’m not bothered ... I told me mates and then people must of just found out but yeah everyone knows I don’t care” (male, aged 17).

Although they did not make any distinctions between their peers in terms of who they would disclose to they did distinguish between the reactions of those considered friends and those not. Those peers not classed as friends were perceived to be the ones who would react most negatively. However, the young people felt that this was not their problem:

"If anyone's got a problem then fuck them cos it's their problem not mine" (male, aged 18).

"You always get the idiots saying stupid stuff like can I catch it but I don't care you just ignore it cos it's not like they're your mates or anythin" (female, aged 18).

"Some people do treat ya like I dunno just horrible like there's something wrong with ya and they'll just be stupid about it erm, like there used to be lads in the year above and they'd just be like don't go near him ya might catch something just stupid things like that" (male, aged 17).

These young people would go to great lengths to achieve a normal life and construct a normal identity. Unlike their other peers they perceived that friends were people who could see for themselves that they led a normal life and that having CF did not make them in any way different:

"My mates know what I'm like anyway you know it doesn't make a difference I'm just a normal lad who does normal stuff with me mates" (male, aged 17).

"My mates can see for themselves that I'm just normal it's not like there's anything I can't do"
(female, aged 18).

Disclosure to peers did not serve a specific purpose. Friends were not deemed to be a viable source of support in dealing with their condition as they felt it was not possible for those who don't have CF themselves to understand what it means to live with the condition:

"I never talk to me mates about it I wouldn't want to they wouldn't understand anyway" *(female, aged 18).*

"To be honest with ya unless you've got CF then there's no way you can understand what it's like" *(male, aged 18).*

Telling potential girlfriends or boyfriends was much more problematic than telling friends as they were people who would want to know more about the condition and explaining it to them was difficult and potentially embarrassing. This was impacted upon by the little belief that there is very little knowledge and understanding of CF amongst those not directly affected by the condition:

"When it comes to lads say like meeting a new lad its horrible I hate it I hate having to tell lads you've got it ... you just think they'll think you're horrible" (female, aged 18).

"People don't know what it is or how many people have it and people should be more aware and then it would be a lot easier to tell people cos they would know what it is instead of me always having to explain" (male, aged 18)

"I hate having to explain it to girls it's really hard cos you just don't know how to put it and it can be really embarrassing like are you supposed to say yeah I cough up loads of horrible phlegm?" (male, aged 17).

Summary of subgroup 3

For these young people having CF is not normal, it is something they fear could prevent them from leading a normal life and being perceived as a normal person. They actively rejected CF in the construction of their identities and they strove to achieve a lifestyle comparable to that of their healthy peers. Their primary way of coping with CF was to not let it be a priority. They achieved this by distancing themselves from their condition and rejecting anything that served as a reminder of it.

They reported being non adherent on a regular basis as adherence to a daily treatment regime was perceived as something that would set them apart from their peers. They felt that others placed too much emphasis on their condition and consequently refused support offered to them from various sources.

They were acutely aware of the progressive nature and limited life expectancy of people with CF and subsequently felt they should live for the now and enjoy life whilst they could. Believing the course of their condition to be highly unpredictable and likely to change with little fore warning resulted in any hopes and aspirations for the future being held in abeyance. Whilst they expressed the attitude that they would not let CF prevent them from doing anything the reality was that they anticipated it would prevent them from achieving their goals for adult life.

They expressed a fear of being perceived as different to their peers. It was important to them that others did not look upon them with pity or sympathy and thus treat them differently. Despite this they did not attempt to conceal their condition from others. Disclosure to peers was a spontaneous act rather than a conscious decision. They did not fear a negative reaction from those they considered as friends as they anticipated that they would see for themselves that having CF did not make them different in any way.

5.7 Feedback

As noted in section 4.2.4 following initial analysis I provided participants with written feedback on their interview and invited them to give their thoughts and opinions on the initial interpretations that had been made. None of the participants responded to the feedback provided. However, I had stated that if they did not reply I would assume that they agreed with the interpretations made. Therefore, I could only assume that this was the case.

CHAPTER 6

DISCUSSION

Section 6.1 will first provide a discussion of the findings within each of the seven salient categories identified. Findings for each of the categories will be linked back to the relevant literature as reviewed in Chapter 2. Section 6.2 will then return to the initial objectives of the study to address how the findings of the present study can add to and expand upon current knowledge and thinking. In section 6.3 the limitations of the study will be identified and finally the implications of findings from the present study for both practice and future research will be discussed in sections 6.4 and 6.5.

6.1 Discussion of the salient categories

6.1.1 Being normal

Being normal and leading a normal life was of primary importance to all of the young people. However, the notion of normality held very different meanings and connotations. The way in which they conceptualised normality within the context of their own lives had far reaching consequences. Like the chronically ill participants in Thorne's (1993) study, the idea of normal held much meaning for participants in the present study and normal was often cited as a reference point from which they described their own personal experiences.

As reviewed in section 2.2, sociologists have identified a number of different forms that the process of normalisation can take for those with a chronic illness and Joachim and Acorn (2001') noted that researchers who study chronic illness through a normalisation lens tend to describe the process as one of actively adapting to changes wrought by the condition. Findings of the present study have highlighted how normalisation can take a variety of forms depending upon the way in which a person conceptualises normality within the context of their own lives.

For those in subgroup 1, living with CF was perceived to be a normal part of their lives, as it was all they had ever known. Normalisation for these young people was not a process of adapting to changes brought on by CF. They did not express a desire to lead a normal life, they explicitly stated that they were normal and did lead normal lives. CF was just one part of this normal life.

Like many of the participants in Thorne's (1993) study, the experience of chronic illness had affected their sense of what normal was and through normalisation the work of managing their condition became a normal part of daily life. For some this had been a subconscious process but others had questioned the meaning of normality and concluded that it holds different meanings for different people. In the context of their own lives, being normal included living and dealing with CF. This reconstruction of normality enabled them to create and maintain a positive attitude towards living with CF as it was not perceived to be something that prevented them from leading a normal life.

In contrast to those in subgroup 1, those young people in subgroups 2 and 3 did not perceive living with CF to be a normal life. Normalisation was a strategy they used, to varying degrees,

in an attempt to lead a normal life. Being normal for these young people was equated with achieving a lifestyle comparable to that of their healthy peers. As noted in section 2.5, adolescence is a time when peer relationships undergo important changes as young people seek to grow more independent of their families. Consequently peer groups and friendship groups can become an important point of reference in social development and peers can encourage conformity to standard norms and values (Hendry *et al.* 1993). For those in subgroups 2 and 3 their healthy peers were an important point of reference as they were epitomised as being normal and leading normal lives, something they themselves aspired to.

For those in subgroup 2 living with CF was not a normal life but they attempted to lead as normal a life as possible. This required effort on their part to strike a balance between the CF and its demands and other areas of importance in their lives. This is consistent with the description of normalisation provided by Strauss *et al.* (1984). For these young people normalisation was a strategy they used in an attempt to establish and maintain as normal a life as possible. The extent to which this was possible varied according to their health status and was particularly difficult in times of ill health which is again consistent with the definition of normalisation advocated by Strauss *et al.*

Like the adolescents with chronic illness interviewed by Woodgate (1998), these young people felt that living with a chronic illness was sometimes hard. Striking a balance required both physical and mental effort, particularly so during times of ill health. Whilst they endeavoured to lead as normal a life as possible their condition was at times restricting and required them to make sacrifices in other areas, such as their social lives.

As outlined in section 2.8, the desire of young people with CF and other chronic illnesses to lead a normal life and be perceived by others as normal has been a thread running throughout previous qualitative research findings. Such research has conceptualised normalisation as a positive strategy that enables them to lead fulfilling lives. This is consistent with the findings for subgroups 1 and 2. However, I argued that it was questionable whether the process of normalisation for young people with CF had been explored in enough depth as research has thus far failed to address the potential negative consequences of normalisation. Thorne (1993) found that whilst normalisation presented a number of advantages for the chronically ill, for others it could create serious problems and lead to a denial of the implications of their illness. She concluded that normalisation is a double edged sword with beneficial consequences under some circumstances and crippling ones under others.

For those in subgroup 3, CF was seen as something that could prevent them from leading a normal life and being perceived as normal by others. Like those in subgroup 2, being normal for these young people was equated with achieving a lifestyle comparable to that of their healthy peers. However, this was taken a stage further as they not only conceptualised normal as being able to act and behave like their peers for these young people it also meant doing so without worrying about the implications for their health.

Unlike those in subgroup 2 they were unwilling to make sacrifices in other areas of their lives. Social life and activities with peers were of prime importance and always took precedence over their condition and the management of it. In their attempts to lead a normal life these young people rejected anything that served as a reminder of their condition and may subsequently make

them stand apart from their peers. This was primarily seen in terms of their non-adherence to treatment and rejection of support from others, actions that could potentially hold very negative consequences for them later on in life (this will be discussed further later on).

Findings of the present study have highlighted that the process of normalisation is complex and is indeed a double edged sword. For the young people in the present study normalisation took a variety of forms and was utilised to serve a number of different purposes. Whilst it served as a positive strategy for those in subgroups 1 and 2, for those in subgroup 3 it held potentially very negative consequences.

In addition findings have highlighted that establishing and maintaining a sense of normality was a key task for young people in the present study as they made the move from adolescence to adulthood. Like the young people in Palmer and Boisen's (2002) study they all felt they had achieved a sense of normality in their lives at present. However, they varied in the extent to which they felt it would be possible to maintain this as they moved further into adulthood. Those in subgroups 1 and 2 were optimistic that in spite of their condition they would be able to attain a relatively normal adult life, maintaining the sense of normality they had already achieved in their lives. They acknowledged that doing so may be difficult at times and they may require support the support of others but ultimately they anticipated that they would make the transition to adulthood, achieve their goals and aspirations and thus lead relatively normal adult lives.

For those in subgroup 3 however, the transition to adulthood in many respects signified a loss of normality. They anticipated that as their condition progressed and their health deteriorated that

maintaining the sense of normality they currently had in their lives would become ever more difficult if not impossible. Therefore, they were reluctant to think about their futures as having CF was something they anticipated would prevent them from achieving normal adult lives. Instead they focused on their lives at present where the establishment and maintenance of a sense of normality was achievable.

6.1.2 CF and Me

As noted in section 2.5, adolescence is a time when individuals begin to form a solid sense of identity and the ways in which young people perceive themselves can greatly affect their subsequent reactions to various life events. All the participants identified themselves to some extent as a normal young person. However, the ways in which they achieved and maintained this identity and the extent to which they felt that CF constituted a part of their identity varied greatly between the subgroups.

There is an interest within both sociology and disability studies of the identity of those who are chronically ill or disabled. As outlined in section 2.3, within disability studies identity is often presented as fixed and a rapidly growing body of literature suggests that disabled people are beginning to assert a positive identity in being disabled and actively rejecting the dominant value of normality.

The same cannot be said of the young people in the present study as whilst some recognised that normality may mean different things to different people they all aspired to achieving a normal

identity. Darling (2003) noted that a number of variables might affect identity including the nature and visibility of the impairment. None of the young people identified themselves as disabled and the relatively low visibility of CF gave them the option to establish and maintain a normal identity.

Kelly and Field (1998) noted that chronic illness may not always be disruptive to a person's identity and consequently they may not feel it necessary to attempt to pass as normal. For those in subgroup 1, CF was not disruptive to their identity as a normal young person; it was a stable aspect of their identities and something that provided shape and meaning in their lives.

In his study of disabled people Watson (2003) found that for some participants their identity involved a reconstruction of normality. The same can be said of those young people in subgroup 1 as whilst they anticipated that others may not view their lives as normal to them it was the only life they had ever know and had therefore become their normal. CF did not define who they were or how they lived their lives but they acknowledged that it was an important part of their lives and an important part of who they were. They did not need to pass for normal, as in their own eyes they were normal.

In their study of adolescents with CF Christian and D'Auria (1997) found that as they had matured participants had begun to realise that comparing themselves with healthy peers was the wrong standard for their lives. Differences due to having CF meant they had to discover a new baseline for their lives to reduce a sense of difference and this was achieved through meeting others with CF. The young people in subgroup 1 also acknowledged that comparing themselves

with healthy peers was the wrong standard for their lives but this was not due to feeling a sense of difference. They recognised that having CF made their lives different to those of their healthy peers for example, the need to carry out a daily treatment regime. However, they perceived these differences to have little or no consequences in terms of their ability to lead a normal life. In fact they embraced such differences as they were viewed as simply a part of their normal lives.

Unlike those in subgroup 1 the young people in subgroups 2 and 3 had actively sought ways to manage their condition that did not impinge on their identity as a normal young person. Those in subgroup 2 also acknowledged the differences between themselves and their healthy peers but similar to some of the participants in Watson's (2003) study they attempted to base their identities on what they could do rather than what they could not do. Badlan (2006) found that some of the young people with CF she interviewed expressed feelings of ambiguity in determining whether they were normal or abnormal as whilst their lives included many social norms they also included some differences not considered normal. The young people in subgroup 2 also saw themselves as both normal and different at the same time but they attempted to overcome this by placing much effort into making the differences not matter as they tried to lead as normal a life as possible.

Unlike those in subgroup 1 they felt that accessing a mainstream identity was something that required effort on their part not something that could just occur naturally. CF was just one of many bases upon which they constructed their identities, it was an important part of their everyday lives but it did not constitute their primary identity. Their relationships with others,

membership of groups and social roles that they performed all formed an important part of their identities.

At times maintaining the identity of a normal young person required them to sideline their CF and downplay its significance to others so they could pursue what they perceived to be normal relationships and social roles integral to becoming an adult e.g. the role of student and relationships with partners. However, illness posed a threat to these relationships and roles and therefore during times of ill health maintaining the identity of a normal young person became difficult if not impossible. During such times they were required to take on the role of patient, which subsumed all other roles and relationships.

One way in which they attempted to maintain the identity of a normal person, even in times of ill health was to compare themselves with others with CF (both real and imagined) who they felt were worse off than themselves. This helped them to feel that their lives were relatively normal in comparison to others with the same condition. As discussed in section 2.4.6, social comparison among those with a chronic illness is considered to be a common event. Similar to the findings of Taylor *et al.* (1983) the young people made downward comparisons in order to feel better about their own situations and where a person who was considered worse off was not available through personal experience, then such a person was imagined.

Watson (2003) also noted that some of the participants in his study rejected physicality and thus their impairment as a determinant of their identity. This was true of those young people in subgroup 3, who actively rejected CF in the construction of their identities. They did not

describe themselves as normal, they were striving to be normal and achieve a lifestyle similar to that of their healthy peers. CF was seen as a potential barrier to this and consequently they felt the need to reject CF as an aspect of their identity in order to access a mainstream identity as a normal young person. Their desire to be normal was so strong that they would attempt to function and behave normally without the support of others and reject anything that served as a reminder of their condition.

Like those in subgroup 2, they compared themselves to others with CF. The majority of their social interaction was with their healthy peers but an exception to this was when they were admitted to hospital. When in hospital they would talk with others with CF, identify themselves as a young person with a chronic illness and acknowledge the impact the condition had on their lives. However, interaction with others with CF was kept separate to interaction with their healthy peers and therefore did not pose a threat to their identity as a normal young person.

They made both downward and lateral comparisons with others with CF. They anticipated or perhaps just wanted to believe that all young people with CF would have a similar attitude towards the condition as themselves and used lateral comparisons to confirm this. Downward comparisons provided justification for their attitude towards their condition and subsequent actions such as non-adherence, as compared to others they felt they were doing relatively well in terms of their current health status.

Watson (2003) questioned whether a shared identity amongst disabled people does indeed exist. Similar to his research, findings from the present study highlight that not all young people with a

chronic illness share a common perspective or identity. The young people in the present study all identified themselves as a normal young person to some degree. However, the extent to which they perceived that CF constituted a part of this identity varied greatly and was dependent upon the way in which they conceptualised normality within the context of their own lives.

For those who felt that CF was just a part of their normal lives the CF also constituted a stable aspect of their identities as a normal young person. For those who sought to strike a balance that enabled them to manage their CF as well as lead a normal life as possible, CF was just one of the many bases upon which, they constructed their identities. Those who saw CF as something that could prevent them from leading a normal life consequently rejected CF in the construction of their identities. Admi (1996) concluded from her study that CF held little relevance to the participants' self image or identity as they did not perceive themselves to be sick, deviant or victims. I would argue that CF did hold relevance for the identities of the young people in the present study. Whilst they too did not view themselves as sick, deviant or victims, CF did play a role in the construction of their identities. For some this was because CF was perceived to be an important part of who they were others however, actively searched for ways in which they could reject CF as part of their identities and thus present to others the image of a normal young person. Either way it was evident that the CF did hold relevance.

None of the young people wanted to be perceived by others as an ill person first and foremost. They did not want others to pity or feel sorry for them. This was a particular concern for those in subgroup 3. Their biggest fear was that having CF might prevent them from leading a normal life and from being perceived by others as normal. They went to great lengths to achieve a

normal life but this was only deemed to be possible if others viewed them as normal. Therefore, they attempted to minimise any differences between themselves and their peers and hence reduce the potential for stigmatisation.

Previous research has also highlighted stigmatisation as an issue for young people with a chronic illness. When asked what the worst thing about CF was, almost one quarter of the respondents in Pownceby's (1995) study cited stigma and discrimination. Consistent with findings from previous research with chronically ill young people, those in subgroup 3 were reluctant to speak about their condition for fear of stigmatisation (Gjendegal & Wabl, 2003) and they engaged in stigma management even when they had no actual experience of stigmatisation (Schur *et al.*, 1999).

The concept of stigma has been of interest to both sociologists and social psychologists for a number of decades. As reviewed in section 2.2, sociologists have been concerned with the ways in which, stigmatisation occurs as a product of the relationship between society and people with a chronic illness (Joachin & Acorn 2001¹). Stigmatisation is described as the process in which social meaning is attached to behaviours or individuals and occurs when evidence exists of an attribute that makes an individual different and less desirable (Goffman, 1963). All of the young people expressed concern that others may treat them differently because of their condition.

Goffman argued that stigma could be understood as the discrepancy between an individual's desired and actual identity. For all of the young people being pitied by others or having others feel sorry for them because of the CF was something that they felt posed a threat to their identity as a normal young person.

As reviewed in section 2.4.5, social psychologists have been particularly interested in the psychological effects of stigma. Major and O'Brien (2005) noted that a social psychological perspective of stigma highlights the variability across people, groups and situations in responses to stigma. Very few of the young people felt they had been stigmatised because of their condition however; they all felt it possible that they may be at some point in their lives. They varied in the ways they felt they would respond to stigmatisation.

Those in subgroup 1 felt that if they experienced a negative reaction towards their condition they would be able to rise above it. Those in subgroup 2 anticipated that stigmatisation would make dealing with their condition even more difficult than it already was. Those in subgroup 3 expressed the view that if someone had a problem with their condition then it was not their problem. However, these were the young people who expressed the greatest concern about being treated differently. They were of the belief that they could only lead a normal life if others viewed and treated them as normal young people and therefore they were the group for whom stigmatisation would likely have the most significant consequences.

There was a consensus amongst the young people that the media portrayal of CF served to increase the likelihood of stigmatisation. As noted in section 2.3, disability theorists have drawn attention to the media as playing an important role in the oppression of disabled people. All of the young people felt that what little there was in the media about CF presented a worst case scenario and depicted those living with the condition as very ill and incapable of leading any kind of normal life. This could lead to others pitying them or feeling sorry for them and thus undermine their identities. They felt that those who knew anything about CF would likely hold

misconceptions about the condition due to an overly negative and inaccurate portrayal within the media. The young people in Admi's (1996) study also felt that most people did not know about CF and those that did usually just knew of the shortened life expectancy. They made a distinction between those who knew someone with CF and those that didn't, with the latter holding more misconceptions.

The misconceptions held by the general public regarding their condition were clearly an issue of concern to the young people in the present study. They did not want to be pitied or viewed primarily in terms of their condition but felt that the media portrayal encouraged others to do just that. They wanted to see a more positive portrayal of CF within the media and in particular a portrayal that showed how young people with CF are able to lead normal lives. This they felt would serve to allay some of the misconceptions held by the general public. In addition some of them also felt that such a portrayal would provide them with positive role models. They wanted to see and hear about people with CF leading normal lives and making the successful transition to adulthood. This could in turn give them hope for their own futures and encouragement to achieve their aspirations for adult life.

Stigma attached to their condition was also perceived by some of the young people as something that may impact their goals and aspirations for the future thus making the transition to adulthood more difficult. Some of the young people were concerned that employers may discriminate against them due to their condition and others worried how prospective partners may react. These concerns impacted upon the young people's decisions about disclosure as discussed in the next section.

As reviewed in section 2.2 Joachim and Acorn (2001¹) noted that researchers typically study and interpret the chronic illness experience through a lens of either normalisation or stigma. They argued that in order to capture and understand the experience of those with chronic conditions researchers should consider both of these perspectives to enable a broader and more accurate understanding, something the present study did. A consideration of both perspectives enabled me to interpret both the relationship between the young people and society and the power of the social context as well as the ways in which they used the process of normalisation to cope with their condition, feel part of society and minimise the potential for stigmatisation by others.

6.1.3 Telling others

As reviewed in section 2.2, coping with stigma, or in the case of many of these young people coping with the fear of stigma, involves various strategies including decision about disclosure (Joachim & Acorn2000²). Those with a chronic illness may find it difficult to disclose for fear of a negative response from others and it has been argued that the management of information in the lives of people with chronic illness is crucial (Joachim and Acorn 2000²).

The issue of disclosure to peers was important to the young people in the present study. They displayed a range of disclosure patterns ranging from not telling any of their peers to openly telling anyone regardless of how well they knew them. Many fell in between the two extremes, choosing to disclose only to those peers they felt should know. For some, disclosure was a spontaneous event whilst for others it occurred only after very careful consideration. This is consistent with the findings of Joachim & Acorn who reported that those with invisible illnesses,

such as CF, disclosed either in a spontaneous manner or in a protective manner where they control how, what, when and who is told about the condition.

Lowton (2004) interviewed adults with CF and found that they classed friendships as medium-risk situations. Consistent with her findings for those in subgroups 1 and 2 the perceived reaction of others influenced their decisions about disclosure and the risks and benefits of disclosure were carefully considered.

Lowton also noted that the perceived level of intimacy with friends was a significant factor and decisions were often based on the quality of a relationship. This was particularly true for those in subgroups 1 and 2 who only disclosed their condition to those they perceived to be good or close friends and the issue of trust was pertinent in their decisions.

Those in subgroup 1 made a clear distinction between acquaintances and friends. They did not disclose to those considered acquaintances as they had not yet earned their trust and they did not yet know them well enough to be able to gauge their reaction. Acquaintances were people they would conceal their condition from sometimes going to great lengths to do so. A good friend was someone that could be trusted not to tell others and also to not treat them differently after learning of their condition.

As outlined in section 2.8.6 Pownceby (1995) found that some young people with CF had difficulty in disclosing their condition to friends for fear of not being socially accepted, exciting sympathy or having their identity reduced simply to the fact of their CF. These were issues of

concern to those in subgroups 1 and 2 and consequently decisions about disclosure were always conscious ones. In an attempt to avoid negative reactions of others towards their condition they ensured they remained in complete control of who knew about their condition. The concealment of CF from peers has also been reported in previous research by Christian and D'Auria (1997).

It is thought that the issue of visibility has implications for decisions of disclosure. A discreditable condition is one that is invisible and hence not yet discredited and this can create the problem whether to disclose the condition or attempt to pass for normal (Goffman, 1963). In his study Quinn (1996) found that some people with CF took the extreme measure of not telling anybody about their CF, but only one of the young people in the present study chose to do this. Given the emphasis that those in subgroup 3 placed on being treated as normal, their fear of being stigmatised and the relatively low visibility of CF I found it surprising that none of them attempted to pass for normal. For these young people disclosure was more of a spontaneous act than a conscious decision and they would openly tell their peers they had CF regardless of how well they knew them.

One explanation for this is the lack of control they felt they held over their condition. They saw CF as something out of their control and consequently also felt that others knowing about their condition was not something they had much control over. They did not make a conscious decision to disclose it was more a case of "if it happens it happens". Also, whilst they did not make any distinctions between their peers in terms of who they would disclose to they did distinguish between the potential reactions of those considered friends and those not. The reactions they were most concerned about were those of people they considered to be friends.

They did not feel it necessary to pass for normal as they anticipated that their friends could see for themselves that they lived a normal life in spite of their condition and that having CF did not make them in any way different.

The transition to adulthood is typically a time when young people become involved in more serious relationships and is therefore a time when those with CF are confronted with the decision of whether to disclose their condition to partners. In Lowton's study participants classed disclosure to a potential partner as a high-risk situation. In this situation disclosure was perceived to hold great difficulty due to the significance of possible consequences. Those in subgroup 3 would openly tell their peers that they had CF but found it much more difficult to tell potential girlfriends or boyfriends as unlike friends they would want to know more about the condition. They found explaining their condition difficult and potentially embarrassing and believed doing so might affect that person's view of them and thus hinder the possibility of a relationship. Similar to previous research these findings indicate that some young people with CF may need advice on disclosing their condition in positive ways.

The transition to adulthood is also the time when most young people will move from education into employment, which again raises issues for young people with regards to disclosure of their condition. Those in subgroup 1 stated they would always disclose their condition to prospective employers to avoid problems later down the line if they became ill. Conversely those in subgroup 2 were extremely wary of disclosing to prospective employers for fear of discrimination.

Findings of the present study are consistent with those of Admi (1996) in that they highlight how the management of potentially stigmatising information for those with CF is a complex and dynamic process. The issue of trust was pertinent for many in their disclosure to peers.

Attitudes towards and decisions about disclosure were also impacted upon by the level of control the young people perceived they had over their condition. Those in subgroups 1 and 2 felt that they themselves had at least some control over their condition and subsequently they chose to be in control of whom they disclosed to. In contrast those in subgroup 3 perceived that they had very little if any control over their condition and subsequently little control over who knew about their condition. The issue of control was also pertinent in attitudes towards and decisions about adherence to treatment and is therefore discussed further in the next section.

6.1.4 The role of treatment

As noted in section 2.4.4 poor adherence to treatment is well documented for those with chronic illness. The young people in the present study reported varying levels of adherence to their prescribed treatment regimes. Studies have found that complete adherence for those with CF is rare and in Pownceby's (1995) study only 15% of participants rated themselves as totally adherent. In the present study it was only those in subgroup 1 who reported being adherent all of the time. For these young people carrying out their prescribed treatment regime was very much a priority in their lives. It was something they had always had to do and therefore it was seen as just a normal part of their lives. Like many of the participants in Gjendegal and Wabl's (2003) study they tended to regard extraordinary events such as adhering to a time consuming treatment regimes, as normal within the context of their own lives.

As reviewed in section 2.8.5 a number of factors have been found to influence adherence in adolescence. In her study Kyngas (2000) identified a number of factors that promoted adherence that are relevant to those in subgroup 1 these are:

- A strong sense of normality – these young people viewed themselves and their lives as normal. Living with and managing their CF was a part of their normal lives.
- A positive attitude towards the disease and treatment – they expressed a very positive attitude towards their condition believing it to be an important part of who they were. They also expressed gratitude that treatments were available to keep them as well as possible. In contrast to the findings of Abbott *et al.* (1994) these young people focused on the long term rather than the short-term benefits of treatment. They anticipated that adherence to treatments would in the long term keep them in the best health possible and thus enable them to achieve their aspirations for adult life. Treatment was very much seen as a facilitator rather than a barrier to leading a normal life.
- Experience of results – they all felt that adherence to treatments was what kept them in the best health possible. Comparing themselves to others with CF whom they perceived to be worse off also provided proof that adherence to treatments was what kept them healthy as they anticipated that those worse off were, unlike themselves, not fully adherent to their treatment regimes.

- Support from parents, nurses and doctors – they all felt they had been encouraged to take responsibility for their own health care and this was something they embraced positively. They also had high levels of trust in both their parents and health care professionals that the advice given to them regarding treatment was in their best interests. In return they felt that they were trusted to carry out their treatment regimes. With the support of their parents they had established daily routines for their treatments from an early age and this helped to minimise the impact treatment had on their lives. Their parents also still provided practical support when necessary such as doing IV's at home to avoid a hospital admission.

Admi (1996) noted that the participants in her study had found ways to routinise and modify their treatment regimes in order to maintain health and reduce interference with their social lives. In the present study, those in subgroup 2 expressed a similar approach. Whilst treatment was not necessarily a priority in their lives keeping well was. They aspired to lead as normal a life as possible but this was not pursued at the expense of their health. They sought to strike a balance between keeping as healthy as possible and still being able to do all of the other important things in their lives.

Abbott *et al.* (1994) suggested that it might be an unrealistic goal to expect young adults with CF to adhere strictly to their treatment regime whilst trying to strike a balance between their needs and their daily regime. Those in subgroup 2 felt that complete adherence was an unrealistic goal. They were willing to take what they felt were considered risks such as missing treatments occasionally if they felt they couldn't fit them in. Over time they had learned to gauge the level of adherence necessary to keep them well although they did not always get this right. When they

fell ill and perceived this to be directly related to their level of adherence this served as a motivator to not only increase their adherence but also take other measures to keep well such as exercise.

The type of non-adherence these young people spoke of has been described by Foster *et al.* (2001) as imposed non-adherence meaning that it is due to external forces. They felt it was not possible to be fully adherent due to practical restraints such as time pressures. The most problematic aspect of their treatment regime was physiotherapy as this was the most time consuming. As reviewed in section 2.4.4 previous research has highlighted the problematic nature of carrying out physiotherapy for those with CF and studies have consistently shown low rates of adherence to it.

Striking a balance between the management of their condition and other areas of importance in their lives was at times a struggle for these young people. As reviewed in section 2.4.4 the support of others has been identified as a crucial influencing factor in the adherence of young people. Whilst these young people felt encouraged and supported by health care professionals to take responsibility for their own health care they felt their parents were reluctant to relinquish this control.

Tyrell (2001) suggested that parents might be reluctant to allow their child to function independently for fear they may make choices that compromise their health. This was true for those in subgroup 2 who felt that their parents did not trust them to take sole responsibility for their health care. At times this resulted in them doubting their own capabilities, making the

establishment of independence even more difficult. They wanted to make their own informed decisions about treatment and be trusted and supported by others to do so. This was at times a source of conflict with parents who not only wanted to play a role in their health care but also expected complete adherence.

In contrast to those young people in subgroups 1 and 2 those in subgroup 3 reported being non-adherent on a regular basis. Treatment was seen as something that served as a daily reminder of their condition, the very thing they were trying to forget about. It was something that could set them apart from their peers and result in them being perceived as and treated differently to their healthy peers. Therefore, like those in subgroup 2 non-adherence was to some extent imposed in that it was a reaction to the perceived social pressure to be the same as their peers.

Abbott *et al.* (1994) found that the lowest rates of adherence occurred when there was no immediate risk or discomfort associated with non-adherence. Consistent with these findings those in subgroup 3 spoke of being least adherent to physiotherapy as this was the aspect of their regime they perceived to be most ineffective. They all described themselves as in reasonable health and felt there was no direct association between non-adherence and deterioration of health. Comparison with others with CF thought to be worse off also provided further justification for their non-adherence, as compared to others they felt they were in reasonably good health.

Unlike those in subgroup 1 these young people focused on the short term rather than the long term benefits of treatment. One participant demonstrated this when he spoke of being non-

adherent to CF treatments on a regular basis but fully adherent to his diabetes treatment at all times. Unlike the consequences of non-adherence to CF treatments he believed that the consequences of non-adherence to his diabetes treatment would have a direct impact on his life in the short term and could prevent him from doing things important to him. These young people did acknowledge that non-adherence now might yield consequences for them in years to come but their decisions were based on the perception that in the short term non-adherence did not hold any immediate physical consequences.

As noted in section 2.8.5 adolescence is commonly seen as a time when young people will rebel and refuse to do their treatments (Fitzgerald, 2001). However, each of the subgroups consisted of young people of varying ages. This, like the findings of Pownceby's (1995) study, appears to belie the commonly held assumption that non-adherence is primarily a problem of adolescence.

As suggested by Sawyer and Aroni (2003) the young people in the present study appeared to construct their own versions of adherence according to their personal worldviews and social contexts. Of particular significance was their sense of normality and the potential of a daily time consuming treatment to impact upon this. It has been previously noted that a number of factors can influence adherence (Kyngas *et al.* 2000) and this was certainly the case for these young people. In addition to their concepts of normality adherence was also influenced by medical, emotional and motivational factors as well as their relationships with peers, families and health care professionals.

There was a striking difference in the attitudes towards treatment of those in subgroup 3 when compared with those in subgroups 1 and 2. This can be at least partly explained by the amount of control the young people perceived that they held over their condition. As noted in section 2.4 a major focus within the field of health psychology has been health beliefs and behaviours.

People with an internal locus of control tend to regard events including those related to health as controllable by them. Those with an external locus of control regard events as uncontrollable by them.

Those young people in subgroups 1 and 2 felt that their health status was at least partly controllable by them and thus had an internal locus of control. Having CF was not something they could control but choosing to do treatments allowed them to feel some element of control over their condition. For these young people establishing a sense of control over their condition was crucial in making the transition to adulthood. By keeping themselves as well as possible these young people felt they were giving themselves the best chance of successfully making the transition to adulthood. Non-adherence was equated with a decline in health, which would ultimately prevent them from achieving their goals and aspirations for adult life.

In contrast those in subgroup 3 had an external locus of control. They believed the course of CF to be both unpredictable and uncontrollable which, resulted in the perception that they themselves had little or no control over their health status. Adherence to treatments did not in any way to serve to increase their sense of control over their condition, as they believed that nothing could change the outcome of having CF, which would inevitably be a premature death. The transition to adulthood for these young people was primarily associated with a decline in

health, something they felt they had little if any control over. However, choosing not to do treatments enabled them to feel some element of control over their lives in the present as doing so allowed them to achieve the lifestyles they wanted regardless of their condition.

6.1.5 Becoming an adult

In discussing the transition to adulthood the young people identified similar role transitions to those outlined in section 2.5.2. They perceived the achievement of adult status to involve: transition from school to higher education or employment; independent living; marriage and becoming parents. In addition they also identified the transition to adult care as an important part of becoming an adult for those with CF and this was something all of the young people spoke about. Whilst they held similar views of what the transition to adulthood consists of, their own goals and aspirations for adulthood varied as did the extent to which they felt someone with CF could successfully achieve the adult markers identified above.

As noted in section 2.8 the little qualitative research that has been conducted with young people with CF currently making the transition to adulthood has painted a very positive picture. Admi (1996) found that young people with CF were not preoccupied with thoughts of death and that their overall orientation was towards continuity of lives. Likewise the young people with CF in Palmer and Boisen's (2002) research were found to be making the transition to adulthood with relatively few problems.

However, in the present study whilst this was the case for many of the young people for those in subgroup 3 the picture was not nearly as positive. These young people expressed the view that they did not want others to only see the negative side of CF but when it came to thinking about the future it was the negatives that preoccupied their own thoughts. They also expressed a desire to “live for the now”, to try and forget about the CF and live normal lives like their healthy peers. However, in many ways their outlooks made them very different to their healthy peers. Most young people their age would be looking towards the future, beginning to think about their goals and aspirations for adult life and setting about achieving them. In contrast these young people anticipated an unsettled future. They were reluctant to talk about future plans or their hopes and aspirations for adult life, as they believed the course of their condition to be highly unpredictable and likely to change with very little fore warning.

They appeared to hold their own misconceptions about the condition believing that their health could begin to deteriorate at any given moment with little or no warning. This was something they felt they could not control and as such their only option was to live for the now and enjoy life while they had it. It is unlikely that such misconceptions had come from those close to them as they refused the support of family members, friends and health care professionals in dealing with their condition, preferring instead to deal with any problems they had on their own. They also did not seek information about CF from other sources such as the internet as they tried to avoid thinking about their condition and thus avoided anything that served as a reminder of it.

The main thing they seemed sure of was that due to deteriorating health their lives would be somehow worse in the future than they were at present. Interestingly, based upon their recent

lung function tests the young people in this group had a range of disease severity rankings so their outlook could not be attributed solely to their current health status. In addition they had described themselves as doing reasonably well health wise in comparison to others with CF.

Having expressed the view that they would not let CF stop them doing anything it became apparent as they discussed their futures there were many ways in which they felt having CF could do just that. It was not that they did not hold aspirations for the future as many spoke of a desire to live independently and get married but they anticipated that having CF was likely to prevent them from achieving these things.

Despite having experienced relatively few problems in school as a result of the CF none of them expressed any plans to enter into further education. This could have been related to socio economic status but as no measure had been taken it is not possible to draw any conclusions about this. They had given little thought to the possibility of establishing careers, as they felt there was little point in doing so. They expressed the view that up until now they had not allowed the CF to prevent them leading normal lives but their views on having children contradicted this somewhat. They did not want to have children in case they too had CF and the young people did not want their own children to go through what they had been through which, would suggest that their condition had indeed impacted profoundly upon their lives.

These young people did not speak of feeling unhappy in any way in their day-to-day lives as a result of having CF, as normally they were able to avoid thinking about their CF and the impact it may have on their futures. They felt there was little point in worrying about the progression of

their CF until it happened, as there was nothing they could do to control it anyway. This raises the question though of how they will cope in the future as their healthy peers do begin to achieve their aspirations for adult life and they are no longer able to avoid thinking about their adult lives and the impact of CF. There is a danger that if they do not begin to look to the future and set about achieving their own aspirations then their worst fears are likely to come true as they grow further apart from their healthy peers and the differences between them become ever more visible.

Findings for those in subgroup 3 stand in stark contrast to the previous research outlined above. The literature on the transition to adulthood for those with a chronic illness (reviewed in section 2.6) has highlighted how chronic illness may present young people with a number of significant barriers to the transition to adulthood however these tend to be structural barriers. The greatest barriers to the transition to adulthood for those in subgroup 3 appeared to be psychological and emotional in nature. Their fears that as their condition progresses it will set them apart from their healthy peers, prevent them from achieving their aspirations for adult life and consequently having others perceive and treat them differently had thus far resulted in any future plans being held in abeyance.

In contrast to those in subgroup 3 and consistent with previous research, for those young people in subgroups 1 and 2 whilst having CF affected some of their choices it did not prevent them from pursuing their goals for adult life. They too were aware of how the progression of CF may impact upon their future plans but tried to remain positive about their futures. Unlike those in subgroup 3 they did not anticipate that their health was likely to deteriorate at great speed and

with little warning, partly so because they invested time and effort into keeping themselves well and healthy. They acknowledged that they could not prevent the progression of their condition but by doing treatments they could delay this for as long as possible. Perhaps then the pessimistic outlooks of those in subgroup 3, although they might not want to acknowledge it, can be partly attributed to their non-adherent behaviour. If so then finding ways to encourage and support them to increase their levels of adherence would not only hold significance for their physical health but also their psychological and emotional well being.

For those in subgroup 1 establishing careers, living independently, getting married and having children were all very real possibilities. They felt a normal transition to adulthood was achievable all be it with a little extra support from those close to them. As reviewed in section 2.8.3 studies of adolescents and adults with CF have revealed that many are living full and productive lives into adulthood. Many of these young people had thought about and made plans for their futures and this was something they had been encouraged to do by their families. They anticipated that there may be problems along the way to achieving their goals but were confident they would find ways to overcome them.

When planning for their futures they had considered the CF and how they could achieve their goals without compromising their health. They were all still in some form of education and had given thought to their future careers. For some of them CF had prevented them following certain career paths but they had accepted this and considered alternatives. Living independently was perceived to be the most problematic of transitions as whilst it was important to maintain their independence they recognised that in times of ill health they would require the support of their

families. As reviewed in section 2.8.3 those with CF can find it difficult to achieve independent living and in a UK study Walters *et al* (1993) found that 58% of men and 48% of women with CF still lived with their parents.

CF was not something that would prevent them from achieving their goals and aspirations for adult life but it was something that impacted upon their decisions about the future. As noted in section 2.6, chronic illness can impact upon a young person's choices for higher education.

Those who were planning to go to university had decided to stay at home where they would have the support of their families and would not have to change CF clinics.

Those in subgroup 2 also expressed similar goals and aspirations for adult life as those in subgroup 1. However, they anticipated more barriers to achieving these. As outlined in section 2.6 chronic illnesses can impact upon family dynamics and Boice (1998) noted that adolescents might find it more difficult to achieve autonomy than their healthy peers, as their parents may be reluctant to relinquish control. These young people were concerned that their parents would not support and encourage them to achieve their goals. They felt that at times their parents were overprotective and this had made it difficult for them to establish their independence thus far.

Another factor that these young people felt made the transition to adulthood problematic was a lack of practical support. As reviewed in section 2.8.2 school is often a place where chronically ill young people experience much difficulty. However, these young people reported relatively unproblematic experiences of school. For them the difficulty had begun once they had left school and those that had gone on to further education had felt unsupported there.

Studies of those with CF tend to emphasise that they have good educational and work records (Tyrell, 2001) but they do require flexible employers (CF Trust, 2003). One young person spoke of how he had left a job after feeling he had been treated unfairly by his employer and all of those in subgroup 2 expressed concerns with disclosing their condition to potential employers for fear of discrimination. Walters *et al.* (1993) found that for some people with CF revealing they had CF at interviews reduced the chance of being employed, which would suggest that their fears are justified. As reviewed in section 2.3 disability theorists have been particularly concerned with the way in which disabled people are socially oppressed as a result of social and environmental barriers such as lack of equal access to employment as well as discrimination and prejudice. The experiences of these young people highlight that those with chronic illness may also experience social oppression.

In addition to a perceived lack of support those young people in subgroup 2 also had their own personal concerns and worries to contend with. Like those in subgroup 3 they expressed concerns about the progressive nature of their condition and they anticipated that having CF would make the transition to adulthood more difficult to achieve. However, unlike those in subgroup 3 they did not let this prevent them from making plans for the future and trying to achieve their goals. Living with CF however did create a sense of pressure to achieve the markers of adulthood sooner rather than later, a phenomenon that has not been highlighted in previous research with young people with CF.

Findings of the present study highlighted that whilst some young people with CF do make a relatively smooth transition to adulthood, as previous research has suggested, this is by no means

the case for all. There are a number of barriers that can impinge on the transition to adulthood for these young people, thus making it more difficult. Previous research has highlighted the structural barriers those with a chronic illness may face in making the transition to adulthood but it was evident from these young people's accounts that psychological and emotional barriers are of equal if not greater significance.

As reviewed in section 2.7 in addition to the tasks of adulthood outlined above young people with CF must also contend with the transition to adult care. This was an issue of importance to all of the young people but their views on transition varied.

Like many of the young people in Madge and Bryon's (2002) study those in subgroup 1 had looked forward to taking control of and managing their own health condition. Taking responsibility for their own health care was seen as both an important step towards adulthood and important preparation for the transition to adult care. The transition itself was perceived to be an important stage in their lives and a positive milestone. Those both pre and post transition felt they had good relationships with their health care team and placed a high level of trust in them. Those who had not yet made the move to adult care felt prepared for doing so and those who had already made the move felt the whole experience had been generally positive.

The transition to adult care for those in subgroup 2 was more problematic. Boyle *et al.*, (2001) reported that a common concern of parents was the ability of their child to care for their CF independently but this was a concern not shared by their children. This problem was evident for those in subgroup 2 as they were finding it a struggle to take full responsibility for their own

health care. This was not because they did not want to do so but because their parents were reluctant to relinquish control of this.

It is suggested in the transition literature that throughout the transition process emphasis should be placed on preparation of both the patient and their families (McDonald, 2000) and that there should be a gradual change of emphasis on responsibility from parents to young people (CF Trust, 2006³). However, this had not been achieved for these young people and for those yet to make the transition this was a cause for concern as they anticipated that staff in the adult clinic would expect them to be fully responsible. Staff in the paediatric clinic had tried to prepare them for the move through measures such as seeing the doctor on their own but they still had concerns regarding the move.

Pownceby (1995) found that many young people with CF look forward to being treated in a more adult way. Most of those in subgroup 2 who had made the transition had found it to be a positive move, as staff in the adult clinic were found to be much more understanding of the impact of the treatment regime on their day to day lives. They felt that unlike paediatric staff those in the adult clinic were able to appreciate that it was sometimes difficult to strike a balance between managing their condition and other areas of importance in their lives. They did not expect complete adherence from the young people and would help them to find practical solutions to their treatment related problems.

Sudden transfer of care has previously been identified as a major pitfall of transition (McDonald, 2000) and there is a consensus within the literature that transfer should only occur after a

preparation period and education programme (Viner, 1999). However, for one young person the transition to adult care had been a particularly distressing experience. She had transferred from a peripheral paediatric clinic and unlike those who had transferred from the regional children's hospital she had received no preparation for the move or for adult life with CF in general. She had not been given the opportunity to visit the adult clinic prior to the transition and therefore had no idea what to expect. Learning the potential implications of CF for her adult life had come as a shock and been highly distressing.

For those in subgroup 3 yet to make the transition, the move signified a step towards adult life, something they did not like to think about hence, they were reluctant to make the move. As reviewed in section 2.7 a number of studies have highlighted that transition to adult care is an issue of concern and a challenging time for many young people with a chronic illness. These young people felt that the transition to adulthood was a difficult time for them anyway and they did not want to add to this difficulty by moving to a new hospital. It was anticipated that the adult clinic would be a place where they would see others with CF die. Attempts from staff to talk to them about the move and prepare them had fallen on deaf ears and they attempted to delay the move for as long as possible. Flume *et al.* (2001) also found that patient resistance was a significant barrier to transition.

They were concerned that they would be prevented from mixing with others with CF when in hospital which was something they currently did albeit against the advice of hospital staff. They also anticipated that staff in the adult clinic would be even stricter about their adherence to treatments and thus the level of conflict would be even greater. However, those that had made

the move said they preferred the adult clinic as the staff there were more accepting of their decisions regarding treatment, seeing it as their responsibility and thus their choice.

A key theme throughout the transition literature is that young people should be given the opportunity to visit the adult clinic prior to transfer (McDonald, 2000). Like many of those in Pownceby's (1995) study most of the young people who had made the transition had been given the opportunity to do so and most had found this helpful. Those yet to make the move were aware that they would be given the opportunity to visit the adult clinic beforehand.

It is felt that the transition to adult care should be a multi dimensional process that involves all the important areas in a young person's life (Geenen *et al.*, 2003) and attends to their medical, psychosocial and educational needs (Soanes & Timmons, 2004). However, there was a feeling amongst the young people that the transition process as a whole was geared towards their medical needs with much less regard to their social and emotional needs. As reviewed in section 2.8.4 an issue of concern highlighted in a number of previous studies is that many young people feel they have unmet information needs. This was a concern for those in the present study and similar to previous studies they wanted more information on and discussion about a wider range of topics including: the impact of having a chronic illness on day to day life; advice about jobs and careers, information on the possibility of having children, advice on how to explain CF to others and other social issues.

6.1.6 Being supported

As reviewed in section 2.8.6 social support is regarded as a crucial factor for young people with chronic illness. Kyngas and Rissanen (2004) found the most important members of the young person's support network to be family members and health care professionals. The young people in the present study varied not only in the level of support offered to them but also the level of support they were willing to accept.

For those in subgroup 1 the support of others, especially their parents, was instrumental in helping them deal with their condition. Like many of those in Pownceby's study (1995) they felt they could turn to family members for support when worried about their CF. They spoke of having never been treated differently by their families because of their CF and this had helped them to develop such a positive outlook. Periods of ill health were seen as par for the course with their condition but with the support of their parents they felt able to maintain a positive attitude even in times of uncertainty.

Having CF necessitated reliance on their parents for support at times but this was not perceived to be an infringement of their independence as long as it was necessary and they did not feel overly dependent on others. As reviewed in section 2.8.6 the support of families can have a positive or negative impact for young people with a chronic illness (Kyngas, 2004) and for these young people their support had a very positive impact. They felt their parents had always encouraged them to be independent and make plans for their futures and they anticipated that the support of their parents would help them to overcome any barriers they encountered on the road

to adulthood. Graetz *et al.* (2000) found that families could provide young people with tangible support such as help with treatments. Those in subgroup 1 noted that as well as providing emotional support their parents also provided practical support when needed, for example, by carrying out IV's at home.

Those who had partners felt that they too were a significant source of support and someone they could confide in with any concerns or worries about their CF. Like parents, partners were a source of both practical and emotional support but it was important to the young people that they did not cross the boundary from being a partner into the role of carer.

Pownceby found that around 35% of participants felt they could turn to friends for support. However, for those in subgroup 1 friends were not seen to be a viable source of support for issues relating to their condition. Although most of them had disclosed their condition to close friends such disclosure did not hold a specific purpose. They did not turn to close friends with concerns or worries about CF, as this would then make their friends worry about them. There were times where the young people found they were the ones providing support to their friends when they had become upset after seeing something within the media about CF. They felt it may be beneficial to speak with others with CF but had not done so as they were not willing to risk the possibility of cross infection.

Pownceby found that fewer of the young people in her study turned to health care professionals for support than their friends. However, for those in subgroup 1 health care professionals were

perceived to be a much more viable source of support than their friends. CF nurse specialists in particular were people they felt able to confide in and discuss their worries with.

Compared to those in subgroup 1 the young people in subgroup 2 felt much less supported. They believed that having good support networks were crucial but these were the young people who spoke of the loneliness and isolation they felt in trying to deal with their condition. At times the burden of living with CF became overwhelming and during such times they struggled to find someone they could turn to and confide in.

As for those in subgroup 1 CF nurse specialists were people they trusted and respected, but they had found that opportunities to speak to them in private about personal issues were hard to come by. They did not like to turn to their families, as they did not want to burden them with their worries. They also felt if they expressed concerns to their families this would just heighten their anxiety that the young person could not cope with their condition and would ultimately only serve to increase their over protective behaviour. As noted by Kyngas (2004) for these young people the support of their families was perceived to be negative as communications centred on issues of adherence to treatments and little else. Unlike those in subgroup 1 these young people did not feel they had the full support of their families in making the transition to adulthood and the reluctance of their families to allow them to establish their independence appeared to be hindering them in making the transition.

Close friends and partners were people that they felt able to talk to about the CF and any concerns they had, but whilst they felt it was beneficial to get things off their chest they did not

feel that others could truly understand what they were going through or how they felt. One way they believed this could be overcome was by speaking to others with the same condition but they were unsure how they could go about this due to the risk of cross infection. It was noted in section 2.5 how during adolescence friendships are normally formed with a subset of peers who resemble themselves in certain characteristics so it is unsurprising that they wanted contact with other young people with CF.

Carpenter *et al.* (2004) found that young people with CF would like to chat to others with the condition and were frustrated by the lack of contact. One way to overcome the issue of cross infection is through the use of internet chat rooms and message boards. Kyngas (2004) found these to be an extremely important part of the support network for chronically ill young people as they allowed them to communicate anonymously, freely sharing their emotions. However, like those in subgroup 1, many of them were unaware of internet message boards such as the one run by the CF trust that have been set up so that those with CF can talk to each other.

What these young people wanted more than anything was greater emotional support. They did their best to maintain a positive attitude and lead as normal life as possible but at times this was a struggle. They wanted to be able to speak with someone who was not personally involved in their lives so that they did not have to worry about burdening them.

The young people in both subgroups 1 and 2 expressed dissatisfaction with the varying levels of practical support they had received from social services. Some had experienced minimal contact with a social worker and others none at all. As reviewed in section 2.3 disability theorists have

been critical of the role of professionals in the lives of disabled people. Marks (1999) argued that professionals hold too much power over the individual and act as gatekeepers to a wide range of resources. These young people were aware that they were entitled to receive benefits but had never received any help to do so. Those that had been in contact with a social worker had been promised support that they subsequently didn't receive. This would suggest that young people with CF need to be enabled to access the resources available to them without having to rely on professionals to do so on their behalf. Some of the young people recognised themselves the potential of such services to assist them in making the transition to adulthood thus highlighting the importance of them being easily accessible.

For those in subgroup 3 support, like treatment, was something that could set them apart from their peers. It had the potential to make them feel and be perceived by others as different and therefore they rejected the support of others in dealing with their condition. Unlike those in subgroups 1 and 2 these young people did not want support in making the transition to adulthood as they tried to avoid thinking about the future as much as possible. They had refused offers of practical support in school, as they did not want to stand out from the crowd in any way.

Surprisingly though, unlike those in subgroups 1 and 2, these young people had received much practical support from social services in applying for various benefits they were entitled to and this was perceived to be the one advantage of having CF. It should be noted that this could also have been related to socio economic status.

Although these young people openly disclosed their condition to peers this did not hold a specific purpose for them. Friends were not seen as a viable source of support when it came to

their condition as they did not feel it was possible for anyone who did not themselves have CF, no matter who they were, to understand what it was like to live with the condition. Therefore, the only people with whom they would discuss the CF were others with the same condition. When admitted to hospital they would talk to others with CF and this was the only time they would acknowledge their condition without the worry of feeling somehow different to others.

They felt that both family members and health care professionals placed too much emphasis on their condition, the very thing they tried to avoid thinking about. Like some of the participants in Graetz *et al's*. (2000) study they felt their families engaged in non-supportive behaviours such as nagging and their non-adherence was a source of conflict with their parents and health care professionals alike.

Whilst they did get on with their health care team they would not go to them with any concerns regarding the CF, as they preferred to deal with any problems on their own. Given their fears about the progression of CF and their own futures, this could be particularly problematic as those close to them are unlikely to be unaware of how they feel. Consequently they may be given little or no opportunity to help them work through such issues and allay any misconceptions they may hold about the condition.

There is a danger that difficulties in dealing with their condition may be overlooked, as their actions are also symptomatic of normal adolescent rebellion. As reviewed in section 2.5 adolescence is a time when young people seek to grow independent of the adults in their lives and it is also a time when they are likely to engage in risk taking behaviour. It is therefore

possible that non-adherent behaviour and refusal of support from adults in their lives may be perceived as normal adolescent behaviour. Findings of the present study highlight how important it is that health care professionals do not just assume this is the case, as such behaviours may be reflective of deeper problems the young person has in dealing with their condition and its implications. Those in subgroup 3 who had made the transition to adult care felt that staff there were more accepting of their decisions about treatment thus meaning such problems might not be picked up upon even after they have moved from adolescence into adulthood.

These young people felt they should “live for the now” at least partly due to their fears of what the future might hold in terms of their CF. Living for the now meant trying to forget about their condition and enjoying their lives whilst they could. However this is a potentially vicious circle as “living for the now” entailed for these young people regular non-adherence to treatment, something that may in fact be putting their future health in jeopardy and subsequently increasing the likelihood of their fears becoming reality. How this circle could be broken is something that needs to be explored further and addressed.

As noted in section 2.8.4 previous studies have found that many young people with CF have good relationships with their health care team and most of those in the present study felt they did, particularly so with the CF nurse specialists. However, as outlined above, the extent to which they felt they were a source of support and the extent to which they were willing to accept their support varied. Whilst none of the young people expressed dissatisfaction with their medical care they did want health care professionals to address wider social issues as well as medical

issues. They wanted health care professionals to discuss the wider issues of making the transition to adulthood and not just the transition to adult care.

Participants in Beresford and Sloper's (2003) study stressed that having information on these topics is as important as knowing about the condition and its management. However, they felt that health care professionals were not aware of or interested in the wider implications of living with a chronic illness and this in turn made them reluctant to raise these sorts of issues. As noted in the previous section the young people in the present study wanted more information on a whole range of issues but they too were often reluctant to raise these issues perceiving that the primary focus of health care professionals was medical issues.

6.1.7 Coping with CF

Consistent with previous research, as outlined in section 2.8.1, the young people in the present study coped with their condition in various ways. As noted in section 2.2 Bury (1991) distinguished between coping, strategy and style. Coping refers to the cognitive processes whereby the individual learns how to tolerate the effects of illness and maintain a sense of self worth. Normalisation was the primary way in which all the young people coped with their condition. However, as noted in section 6.1.1 the process of normalisation took a number of different forms for these young people and this then influenced the types of coping strategies they adopted.

For those in subgroup 1 through the process of normalisation they had come to view CF, its implications and its management as just part of their normal lives. Similar to the findings of Lowton and Gabe (2004) maintaining a positive attitude was one way in which these young people coped with CF. Managing their CF and keeping well was a priority in their lives and they were willing to make sacrifices in other areas when necessary. Abbott *et al.* (2001) found that optimism was the strategy most frequently used by their participants to deal with CF. Those in subgroup 1 were both hopeful and optimistic for their own futures and fully anticipated making a successful transition to adulthood. This was reinforced by the development of new treatments and the increasing life expectancy for those with CF. They tried to focus on the positives in their lives and not dwell on the negatives.

They also employed a number of strategies, defined by Bury (1991) as the actions people take in the face of illness to mobilise resources and maximise favourable outcomes, in coping with their condition. These were: seeking both emotional and practical support from others; getting into routines with their treatment regimes; preparation and planning ahead; seeking alternatives when their CF posed a problem for example, seeking alternative career paths if their preferred ones were likely to pose a risk to their health; seeking knowledge on their condition and the management of it; avoiding undue risks to health such as drinking alcohol and being proactive in keeping themselves healthy for example, undertaking exercise in addition to their prescribed treatment regime.

Many of the strategies used fall under the category of problem- focused coping as they are aimed at addressing a specific problem. Badlan (2006) noted that internal control was an important

factor in dealing with CF. As reviewed in section 2.4.3 problem-focused coping is thought to occur in those who accept their illness or believe they may be able to influence it (Schussler, 1992). Findings for those in subgroup 1 support this as they did accept their condition and felt they were able to maintain some element of control over it through adherence to treatments and they also remained in control of decisions regarding disclosure.

For those in subgroup 2 the process of normalisation revolved around trying to strike a balance between their condition and other areas of importance in their lives. Like the participants in Woodgate's (1998) study they did not allow the CF to be their number one priority. They tried to keep things in perspective for example, it was not the end of the world if they missed the occasional treatment but looking at the bigger picture and the potential consequences of regular non-adherence motivated them to keep well. These young people also tried to remain optimistic, they acknowledged that having CF would impact upon their transition to adulthood and in many ways make it more difficult but they did not anticipate that it would prevent them from achieving their goals and aspirations.

They also tried to deal with problems as they arose and not dwell on the negatives although this was not always easy. At times they became overwhelmed by their condition and the implications of it. During such times they would find ways to distract themselves from thinking about the condition for example, by spending time with friends who did not know they had CF.

Occasionally they would use avoidance to help them cope with the condition for example, delaying the move to adult care for as long as possible. Abbott *et al.* also found that some people with CF used avoidance and distraction strategies to cope. Other strategies employed by those in

subgroup 2 were: making reasoned decisions about treatments, minimising the impact of treatment by seeking alternatives for example, if they did not have time to carry out physiotherapy they would use their flutter instead and planning ahead for example, if they knew they were going out they would start their treatment regime earlier. They also sought the support of others but often found this to be problematic.

As reviewed in section 2.4.3 problem-based coping is viewed more favourably than emotion-focused which is considered to be maladaptive. However, those in subgroup 2 used both problem-based and emotion-based coping. Abbott (2003) has suggested that it now appears naïve to ask which coping strategies are adaptive or maladaptive and what we should be asking is which strategies are adaptive or maladaptive for a particular individual against a particular outcome?

Lazarus and Folkman (1984) drew attention to temporal ordering and argued that different coping strategies may be differentially effective during different stages of a stressful episode. For those in subgroup 2 emotion-focused coping strategies such as distraction were only used when they began to feel overwhelmed by the condition. They were not used all the time but appeared to serve as an adaptive strategy during particularly difficult times. This highlights that it is indeed naïve to simply label coping strategies as adaptive or maladaptive without giving due consideration to the context within which they are used.

For those in subgroup 3 the process of normalisation entailed living their lives as though they didn't have CF. They avoided thinking about the CF and its implications as much as possible and

rejected anything that served as a reminder. They did not allow the CF to be a priority at all in their lives. They tended to think in the short term, live for the day and enjoy life while they could. They were neither hopeful nor optimistic and their overall outlook on adult life was extremely pessimistic. Unlike those in subgroups 1 and 2 these young people did not foresee themselves making a successful transition to adulthood due to the progressive nature of their condition. They were reluctant to think about their hopes and aspirations of the future for fear that their CF would make them simply unachievable and avoidance appeared to be the only way they felt they could cope with this.

It is questionable whether this equated to denial as they still attended hospital appointments, spoke about the advantages of having CF such as being able to get a car and perhaps most importantly they openly disclosed their condition to peers. So it appeared that they adopted the style of avoidance rather than denial. The ways in which these young people coped were primarily emotion-focused. They used emotion-focused strategies to avoid thinking about the implications of CF on their adult lives. It is a concern that these young people may not have problem-focused coping strategies to draw upon if and when they do encounter problems relating to their condition in years to come. Schussler (1992) noted that emotion-focused coping is thought to frequently occur in those who consider their illness uncontrollable. Findings from these young people support this, as they perceived the course of their condition to be both unpredictable and uncontrollable.

Bury (1991) defined a coping style as the way people respond to and present important features of their illness. Making downward social comparisons was a style used by all of the young

people but in different ways. For those in subgroup 1 comparing themselves with those worse off provided justification for the amount of effort they invested into keeping well as they assumed that those worse off invested much less effort into keeping well. For those in subgroup 2 downward social comparisons were made during times of ill health and served to provide reassurance that their lives were still relatively normal in comparison to others with the condition. Finally those in subgroup 3 assumed that those worse off were more adherent than them and downward comparisons served as proof that there was little association between adherence to treatments and health status.

As reviewed in section 2.4.4 Abbott *et al.* (2001) found that the ways in which individuals cope with CF may also influence adherence to treatment and findings of the present study support this. They found that optimistic acceptance and hopefulness were associated with greater adherence to treatment. These were the primary coping styles employed by those in subgroup 1, all of whom reported being adherent all of the time. They also noted that those who used distraction strategies were more likely to partially adhere. Those in subgroup 2 reported using distraction strategies and similarly they reported being adherent most but not all of the time. Finally they found that those who employed an avoidant style reported greater levels of non-adherence to physiotherapy and enzyme therapy. Those young people in subgroup 3 adopted an avoidant coping style and they reported regular non-adherence to all aspects of their treatment but mostly so to physiotherapy.

These findings support previous research on coping, which has suggested that young people with chronic illnesses cope with their condition in a variety of ways. It was noted in section 2.4.3 that

a limitation of many previous studies is their sole reliance on coping questionnaires that lack situational detail. The coping strategies employed by those in the present study are similar to those reported in previous studies. However, the approach of the present study has enabled a more comprehensive understanding of coping for those with CF. Normalisation is commonly reported as coping strategy for those with a chronic illness but findings of the present study have highlighted that this process can take number of different forms and this can then influence the types of coping strategies and styles adopted. Findings from the present study also provide insight into why people select a particular coping response in a particular context. In doing so they support the argument of Abbott (2003) that in reality individuals are likely to use a number of different strategies that serve to focus attention both towards and away from the problem.

6.2 Key findings of the present study

The present study began with two overall objectives. The first was to gain insight into the transition to adulthood for those with CF and thus identify what if any barriers or difficulties they face in making this transition. I was aware that young people with CF often rely heavily on services and in carrying out this objective I hoped to identify the ways in which these services could be more sensitive to their needs and priorities.

The second main objective was to consider the experience of living with chronic illness from a much wider perspective than previous research has done. In doing so I endeavoured to broaden and enhance what is currently known about young people's experiences of living with CF. This

section will return to each of these objectives and consider them in light of the findings of the present study.

6.2.1 The transition to adulthood for young people with CF

As reviewed in section 2.8 only a few studies have focused qualitatively on how young people with CF experience their lives. The present study differs from previous research in a number of ways: it focuses solely on the perspectives of young people with CF; it does not rely on retrospective accounts and it focuses on a specific stage of life, the transition to adulthood, for young people with CF.

It was noted in section 2.6 that there is a consensus within the literature that having a chronic illness presents additional challenges in the transition to adulthood but much of this literature is descriptive in nature. There is a lack of research that has addressed the dynamics of the transition to adulthood for young people with a chronic illness in general and even less so for those with CF. Therefore, the present study aimed to provide insight into how young people with CF experience this stage of their lives and to address what if any additional challenges they do face.

As outlined in section 2.6 Shay and Newth (1985) identified a number of specific tasks a young person with CF must accomplish in addition to the normal tasks of adolescence and adulthood.

However, it was noted that their model was developed at a time when life expectancy was much lower than it currently is and consequently fewer people with CF survived into adulthood. I therefore anticipated that the current concerns and experiences of those with CF making the transition to adulthood would differ to those proposed by Shay and Newth.

The accounts of the young people in the present study revealed that the transition to adulthood for those with CF is a time of great change and competing priorities. As discussed in sections 6.1.1-6.1.7 in addition to the normal tasks of transition to adulthood young people with CF have a whole host of additional tasks, pertaining to their condition that they must contend with, these are:

- Establishing and maintaining a sense of normality
- Finding ways to manage their condition that do not impinge on their identity as a normal young person
- Establishing a sense of control over their condition
- Making decisions about the disclosure of their condition to others

- Considering their goals and aspirations for adult life in light of their condition and its progressive nature
- Finding ways to cope with the impact of CF during the transition to adulthood and the implications it holds for their adult lives
- Establishing independence from their families and taking responsibility for their own health care
- Establishing appropriate sources of support
- Making the transition to adult care.

6.2.2 The merging of disciplines

It was argued in section 2.9 that researchers need to broaden their approaches within the fields of chronic illness and disability. The three main disciplines reviewed in Chapter 2; sociology, disability studies and psychology have all been criticised for failing to take account of the whole experience of living with chronic illness/disability.

Typically researchers have considered the experience of chronic illness and disability from within their own particular discipline. A major strength of the present study is that all three of these disciplines were reviewed and thus data was considered from a variety of perspectives. Findings of the present study have highlighted the value of such an approach for example, whilst sociological and disability studies approaches were able to account for the young people's experiences of normalisation and stigma they were unable to account for some of the individual factors that impacted upon these experiences such as locus of control and coping style.

As reviewed in section 2.2 much tension exists between the fields of sociology and disability studies. Sociologists have been criticised for defining impairment as the determining cause of disablement. In contrast disability theorists have advocated a social model of disability, which rejects an individualistic approach and locates the problem of disability squarely within society. Subsequently the focus of much research within this field has been the social and economic disadvantage and discrimination experienced by disabled people (Barnes & Mercer, 1996).

In recent years the social model of disability has also come under heavy criticism. Disabled feminists have been particularly critical of its failure to acknowledge the role played by impairment and illness in people's life experiences. As such the social model has excluded those with chronic illness as it construes a person's bodily state primarily as the subject of social accommodation rather than medical attention. In contrast those with a chronic illness such as CF rely on medical attention to keep themselves well and alive. However, De Wolfe (2003) stressed that this does not mean social arrangement does not have a significant impact on the experience

of illness and it does not mean that those with chronic illness do not experience disability in the form of social barriers. She further argued that those with chronic illness would gain from a widening of the disability movement to specifically include them as they could then begin to articulate their social needs rather than having their illness construed as a purely individual/medical problem.

As outlined in section 2.3 a social relational approach to disability acknowledges that impairment and thus chronic illness may directly cause some restrictions of activity and Thomas (1999) referred to these as impairment effects. Impairment effects do not constitute disability however as disability only comes into play when restrictions of activity are socially imposed.

As noted in section 3.1 whilst I recognised that in having CF the young people in the present study could be defined as living with impairment and as such they would experience impairments effects I did not assume that they had necessarily experienced disability. By speaking to them about their experiences of the transition to adulthood I hoped to identify whether they had experienced disability and if so how.

Thomas (1999) identified two categories that constitute disability: barriers to doing and barriers to being. Barriers to doing are the physical, economic and material barriers that people with impairments experience such as inaccessible buildings. Barriers to being highlight the psycho-emotional aspects of disablism, that is the hurtful, hostile or inappropriate behaviours that have a

negative effect on an individual's sense of self, affecting what they can be or become. Thomas (2001) noted that agents of psycho-emotional disablism may be people close by such as family and friends, individuals in direct contact such as professional or strangers.

A social relational approach allows consideration of both macro and micro influences in the lives of those with impairment as it relates directly to peoples lived experience as well as addressing socially imposed barriers. As noted in section 2.9 it can account for the problems that people experience as a direct result of their impairment and the wider social implications of this, something that sociologists have focused on. It can also account for the socio-structural barriers encountered by those with impairments, which have been a major focus of disability theorists. Finally, it takes into account both the direct psychological effects of living with impairment as well as dimensions of disability that operate along psychological and emotional pathways. Thus it allows the merging of disciplines, something the present study endeavoured to do.

Reeve (2004) suggested that a social relational approach to disability might provide a more accurate account of disability for those with less visible impairments, including chronic illness and findings of the present study support this. Living with CF had both physical and psychological effects on the lives of the young people in the present study and at times these resulted in restrictions of activity. In times of ill health some of the young people noted that they had to make sacrifices in other areas of their lives such as their social lives. Therefore, their condition sometimes restricted activities with peers.

Their condition necessitated numerous trips to hospital usually for clinic appointments but sometimes for longer stays as an inpatient. This too caused direct restrictions of activity. Having CF had also meant for some that they were unable to follow a specific career path due to the negative impact this may have on their health status. For example, some of them noted they would not be able to work in the medical profession due to the increased risk of catching infections.

The young people also spoke of the psychological effects of living with CF. They were living with the knowledge that their condition is progressive and at some point their health status will inevitably begin to deteriorate. They had thought about the implications this may have for their adult lives and acknowledged that as their condition progressed it would likely cause many more restrictions of activity. As discussed in section 6.1.5 the young people varied in the way they dealt with this and consequently the extent to which it impacted upon their psychological well being also varied. However, for those in subgroup 3 their concerns about the progressive nature of CF were causing restrictions of activity in their lives at present. Their fears that their health could begin to deteriorate at any given moment with very little warning was preventing them from thinking about and making plans for their futures.

The effects of their chronic illness and the resultant restrictions of activity noted above do not constitute disability as defined by Thomas (1999) because the restrictions were not in any way socially imposed. The social model of disability argues that a key criterion for inclusion in the Disabled People's Movement is to have a positive identity as disabled (Marks, 1999) However,

many people with chronic illnesses do not necessarily identify themselves as disabled and this was true of the young people in the present study. Consideration of their experiences within a social relational approach though, did indeed highlight that some of the restrictions and difficulties in their lives were not a direct consequence of having CF, they were a consequence of social oppression.

The young people had little experience of barriers to doing although some reported a lack of instrumental support in further education and one young person had left his job after being treated unfairly because of his condition. It is possible that as they move further into adulthood they might experience additional barriers to doing for example, when they move out of the family home. Their experiences did however highlight a number of barriers to being, as defined by Thomas (1999). Findings of the present study support the argument put forward by Thomas (2004¹) that the dimensions of disablism, which create barriers to being need to take centre stage. She noted that this form of disability can shape in a profound way what people can be as well as affecting what they can do as a consequence and this was evident in some of the young people's accounts.

A number of barriers to being can be identified within the experiences of the young people. They all expressed some level of fear that they might be stigmatised because of their condition and they did not want to be perceived by others as an ill person first and foremost. They believed that the main agent through which stigmatisation of the condition occurred was the media. As discussed in section 6.1.2 they felt that what little there was in the media about CF

was overly negative and depicted those living with the condition as incapable of leading a normal life. This could lead to others pitying them or feeling sorry for them and thus undermine their identities as normal young people.

This media portrayal and a general lack of awareness of CF within the general public had, they believed, led to a lot of misconceptions about the condition. This impacted upon their decisions of disclosure to peers, prospective partners and prospective employers. As the media only portrayed the worst-case scenario of living with CF this meant they did not have any positive role models. They did not see or hear of others with CF successfully making the transition to adulthood and for some this resulted in them doubting their own potential for transition.

The fear of stigmatisation had the most profound impact for those in subgroup 3. They strove to lead a normal life and felt they could only do so if others did not perceive or treat them as different in anyway. They therefore, rejected anything in their lives that had the potential to be a stigma symbol. As discussed in section 6.1 they consequently reported being regularly non-adherent and rejecting the support of others in dealing with their condition. Both of which, have the potential to yield negative consequences for their adult lives affecting both who they can be and consequently what they can do.

As discussed in section 6.1.6 some of the young people reported a lack of both practical and emotional support in dealing with their condition. For those in subgroup 2 a lack of emotional

support sometimes left them feeling lonely and isolated. At times the burden of living with CF and its implications for adult life became overwhelming and this made them doubt their own potential for achieving their goals and aspirations for adult life. Therefore, the failure of professionals in their lives to provide them with adequate support also created barriers to being. Parents were also agents of psycho-emotional disability for some of the young people. Those in subgroup 2 found their parents to be over protective because of their condition. This made it difficult for them to establish their independence. They had particular difficulty in taking responsibility for their own health care as their parents were reluctant to relinquish this control which then made the young people doubt their own capabilities to do so.

As demonstrated above a social relational approach to disability was able to account for many of the young people's experiences. The use of this approach allows us to see both the individual and wider social effects of living with CF for these young people. De Wolfe noted that at present there is no political movement of sick people as there is for disabled people but that it should be acknowledged that those who live with illness require social recognition, inclusion and support. The findings of the present study support this and I would argue that we need to stop viewing chronic illness as a purely individual problem and start taking account of and addressing the collective as well as the individual needs of young people with CF and other chronic illnesses.

6.2.3 Summary

Overall I feel the initial objectives of the study have been achieved. The grounded theory methodology adopted for the present study yielded rich and in depth insights into the lives of young people with CF. It was evident from the young people's accounts that the transition to adulthood represented much more than the achievement of traditional markers of adulthood and interpretation of the young people's experiences revealed a number of specific tasks they feel they must achieve during this stage of life, as outlined above. Many of the young people looked forward to the future and achieving their goals and aspirations for adult life. For some however, the transition to adulthood was a stage in their lives that they feared would be marked by deterioration of their condition.

A multitude of both internal and external factors were found to influence this stage of life ranging from internal characteristics of the young people to familial influences to wider societal influences. Therefore, I do not feel it would have been possible to understand and account fully for the experiences of these young people with the use of a single perspective.

The findings of the present study have demonstrated that a social relational approach has the potential to bridge some of the gaps that currently exist between the disciplines of sociology, disability studies and psychology and thereby forge links between illness and disability. As noted in section 2.9 forming allegiances could give people with chronic illness the opportunity to

articulate not just their medical needs but also their social needs, whether they choose to identify as disabled or not. This is something I feel has been achieved in the present study.

6.3 Limitations of the present study

- The present study yielded rich and in depth insights into the experiences of young people with CF however, the size of the sample was relatively small. I believe the findings of the present study have laid the foundations of a substantive theory but due to the sample size they do not yet represent a fully developed substantive theory.
- I had initially hoped to conduct online focus groups with young people with CF in addition to interviews but I was unable to obtain ethical approval to do so. A triangulation of methods would have served to increase the rigour of the present study.
- All of the young people interviewed spoke at length about the transition to adult care and their broader experiences of healthcare. It should be noted that all of the participants were recruited through the hospital setting and the majority of the interviews took place within hospital grounds. It is possible therefore that the reason they spoke about such issues is because they felt obliged or expected to.

- During the analysis stage of the present study I became aware that the participants socio-economic status may have been an influencing factor for some of the variations found for example, the differences found between participants in terms of their educational aspirations. However, no measure of socio-economic status had been obtained so this could not be considered.
- In addition to socio economic status it is possible that other sociodemographic variables could have influenced findings such as family variables. Whilst some of the young people spoke of their family situations in great detail others did not meaning it was not possible to draw any firm conclusions based upon this.
- Disease severity was found to have no influence on findings. However, only one measure of disease severity was taken. Obtaining additional clinical variables would have provided a more accurate measure of disease severity.
- During recruitment at the regional children's hospital all of the young people who fitted the criteria for the study were approached. However, in the regional adults hospital as there was a much larger sample of potential participants it was left to staff members to select who was approached. I had asked the staff members to approach anyone who fit the criteria until I had obtained a large enough sample. However, it is possible that they may have made their own judgments and only approached those who they felt would be most suitable or willing to take part.

- As noted in section 3.4 in grounded theory research it is considered most useful to conduct multiple interviews with each participant. However, due to time constraints it was not possible to do so in the present study.

6.4 Implications for practice

The findings of the present study have highlighted a number of implications for the practice of professionals who play a role in the lives of young people with CF. This section will outline a number of ways in which, practice could be changed in order to better serve the needs of young people with CF.

Findings of the present study revealed three very different subgroups of young people with CF. The place and significance of CF within their lives varied greatly according to these subgroups. There were those who felt that they were normal despite having CF, those that sought to strike a balance between the CF and other areas of importance in their lives and those who struggled to deal with and incorporate CF into their lives. The young people within these 3 groups will therefore have different needs and it is important for health care professionals to recognise this and provide services that are sensitive to individual needs and priorities.

Levels of adherence were found to vary according to these three subgroups and ranged from total adherence to regular non-adherence. The regular non-adherence of some of the young people appeared to be reflective of the underlying problems they had in dealing with CF and its implications for their lives. Findings of the present study highlighted how important it is that health care professionals do not assume that non-adherent behaviour is simply part of a normal adolescent rebellion as in doing so such problems could be overlooked.

All of the young people felt it was useful to speak with others with CF. However, due to the risk of cross infection most of them were unable to. Most of the young people were not aware of internet forums and discussion boards set up for people with CF, such as those run by the CF Trust. These forums could provide a way for the young people to talk to others without the risk of cross infection. Therefore, it would be beneficial for health care professionals to ensure that young people with CF are aware of these forums and to ensure that the young people have access to the internet during their time as inpatients.

Many of the young people felt that due to the negative portrayal of CF within the media and the lack of contact they had with others with CF that they did not have any positive role models. Seeing or hearing about others with CF leading normal lives and making a successful transition to adulthood could in turn give them hope for their own futures and encourage them to achieve their own aspirations. This could be particularly pertinent for adolescents such as those in subgroup 3 who were fearful of their futures due to the progressive nature of CF and consequently were reluctant to think about or make any plans for their own futures.

A potential way to provide positive role models is through mentorship, an idea raised by the young people in the preliminary stage of the present research. A programme could be set up by hospitals whereby young people are put in touch with an older person with CF who is willing to speak with them about any concerns or worries they have and generally provide them with some support through the transition period. To avoid the risk of cross infection such a programme could be conducted via email or a purposely set up internet chat room. This would also allow the young people to keep their identities anonymous if they so wished.

The young people raised a number of issues regarding the support they received. The support of social services was particularly problematic with many of the young people having had little or no contact with a social worker. They required the support of a social worker in order to identify the various benefits they were entitled to claim and for help in doing so. The variability of support received is something that needs to be addressed and it would perhaps be beneficial for social workers and health care professionals to work together in identifying and addressing the needs of young people with CF.

Some of the young people refused offers of support in dealing with their condition for fear it would make them appear somehow different to their peers and they were also the young people who expressed most uncertainty about their adult lives with CF. They also appeared to hold a number of misconceptions about CF believing that their health status could decline at any given time with very little warning, irrespective of their current health status. It is important that health

care professionals find a way of getting through to these young people and finding a way of supporting them that the young people will accept.

A way this could be achieved is through the use of expert led, moderated, online interventions. These could be set up through forums that have already been established for people with CF. This would be a way for young people with CF to access support that was in no way visible to others. It would also allow them to speak openly and honestly with professionals and to ask any questions they might have whilst remaining anonymous.

Some of the young people expressed a desire for greater emotional support in dealing with their condition. They were reluctant to speak to those close to them and would prefer to speak with someone not personally involved in their lives. Opportunities to do so however, were limited. This highlights the importance of having someone with a counseling role based in hospitals that the young people could be referred to if they so wished.

The young people's experiences of the transition to adult care also highlighted areas of practice that could be improved upon. For most of those who had made the transition to adult care the process had been relatively smooth and unproblematic. However, for one young person it had been highly distressing and her experience of the transition process highlighted the need for an adequate preparation programme. Most of those who had made the transition to adult care had done so from the same regional children's hospital where they felt members of staff had prepared

them for the move. However, this young person had made the transition from a peripheral clinic where she had received no preparation prior to the move. Therefore, it would be beneficial for a set preparation and educational programme to be used consistently by all clinics transferring their patients to the same adult clinic.

All of the young people said they wanted health care professionals to address wider social issues as well as medical issues. In particular they wanted more information on and discussion of the wider aspects of the transition to adulthood that their condition may impact upon such as: finding suitable jobs; having children; living independently and explaining their condition to partners. This highlights the need for health care professionals to ensure that the transition process attends not just to medical needs but also to the psychosocial and educational needs of young people.

The regional children's hospital from which many of the young people were recruited had established a programme of preparation for the transition to adult care. The health care professionals working within the CF unit had devised a transition checklist comprising of all the issues that should be addressed and discussed with a young person in the years leading up to transition. Once all of the issues had been addressed the young person was deemed to be adequately prepared to make the transition to the adult clinic. The issues included on the checklist were both medical and social in nature however, those who had made the transition from this unit felt that many of the social issues had not been addressed. The young people had no knowledge of the transition checklist and I would therefore suggest that it might be more

beneficial if the young people themselves could see the list and sign it once they felt a particular issue had been adequately addressed.

6.5 Implications for future research

As noted in section 6.3 the findings of the present study have laid the foundations of a substantive theory but due to the sample size they do not yet represent a fully developed substantive theory. Therefore, further research is needed to add to and develop the findings of the present study. This could be achieved in a number of ways:

- Key findings of the present study could be used to develop a questionnaire. This would enable access to a much larger sample of young people with CF and the triangulation of methods would increase the rigour of the study.
- Similar research could be carried out with young people with a range of chronic illnesses. This would help to establish whether the findings of the present study are specific to those with CF or if they are representative of the chronic illness experience for young people more generally.

- The present study could be expanded into a longitudinal study. Participants could be re-interviewed each year for the next few years and this would provide greater insight into the transition to adulthood for young people with CF.
- Findings of the present study have highlighted the ways in which those with a chronic illness may be socially oppressed. Future research could use a social relational approach to provide an account of disability for young people with a range of chronic illnesses and thus enable them to articulate their social needs.

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Appendices

Appendix 1: Message posted on CF Trust internet forum

Hi, my name is Joanne and I am a PhD student at Liverpool John Moores University. I am conducting a research project on the transition to adulthood for young people with CF. I will be looking at a number of transitions including: transition from school to further education, employment or training; transition to financial independence, transition to independent living and transition from pediatric to adult care.

Through my research I hope to find out what external factors affect this transition for young people with CF. The factors I feel would be important are, firstly the people around you such as family members and friends and secondly, places such as school and hospital. However, I would really like to give young people with CF themselves to opportunity to identify the factors they feel are important. I would really appreciate it if anyone with CF would reply to this message and let me know whether you feel the factors I have identified are ones that would influence the transition to adulthood. I would also really like to know if there are any other factors you feel would affect the transition that should be included in the study.

A later stage of this research will be to carry out interviews with young people with CF. Your responses will be used to help me devise the interview questions. If you want to respond but don't want this to be used in the study you can just state this. Your identities will remain anonymous at all times.

Unfortunately I will not be able to reply to any of your messages as to do so I would need written consent from both you and a parent/carer. You are not obliged in any way to respond to this message but I would be very grateful to anyone who does.

Many Thanks

Joanne

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UNDER
INSTRUCTION
FROM
UNIVERSITY

Appendix 4: Participant information sheet



Participant Information Sheet

Name of researcher: Joanne Hogan

Supervisor: Dr Maureen Horgan

Title of study/project: Transition to adulthood for young people with Cystic Fibrosis

You are being invited to take part in a research study. Before you decide 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 and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Purpose of study:

The purpose of this study is to look at the experience of the transition to adulthood and the things that affect this transition for young people with CF. This study will be based entirely on the perspective of young people with CF themselves, which I will gather through the use of interviews. If you choose to participate, an interview will be conducted with you. The interview will give you the opportunity to express your thoughts, feelings and opinions on the transition to adulthood and what that means to you. During the interview you will be invited to talk about the following areas:

- Your experiences of the transition to adulthood including: the transition from school to training, further education or employment; the transition to financial independence; the transition to independent living and the transition from pediatric to adult care
- How you feel the people around such as friends and family members influence this transition and your goals for the future
- How places such as hospitals and schools affect you during the move to adulthood
- Whether there are any other things that you feel influence the transition to adulthood
- Whether you feel there are any barriers within society that may hinder or prevent you in making this transition and achieving your goals for the future
- What changes you feel could be made in order to remove these barriers

Throughout this study I will give young people with CF the opportunity to highlight areas that are important to them that have not previously been considered. I hope that this will allow young people with CF themselves to influence services in the future.

Why have I been chosen?

I would like to interview you as we want to be able to understand your thought, feelings and opinions on the various processes of transition that young people your age encounter. I hope that by interviewing you we can begin to have a better understanding of the transition process for young people with CF and how the people around them and services they encounter affect this transition.

Do I have to take part?

No. It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part, will not affect the standard of care you receive.

Procedures and Participants Role:

I would like to conduct an interview with you. The interview will last around one to one and a half hours. During the interview you will be able to take a break or stop the interview at any time if you wish. I will arrange with you a convenient time and place to carry out the interviews. Interviews can be conducted in a private room in the hospital or on university premises or in your home if you prefer. With your consent I would like to tape record the interviews however, nobody else will be listening to the tapes and once they have been transcribed they will be destroyed after six weeks.

Should the interview raise issues you feel you want to discuss with someone other than the researcher, support will be available through the CF Department. If at any time throughout the study you feel you need this extra support you can just let the researcher or any member of the CF team know.

With your permission following the initial interviews I would need to obtain some information from your medical records in order to see how you are affected by Cystic Fibrosis. This would be supplied by one of the medical/nursing team looking after you. Please note that I will not at any time have access to your medical records.

Following the interview I would like to provide all participants with written feedback of the analysis I have made. It will not be possible to identify any participant from this feedback. I will then ask you to give me your comments on the interpretations I have made so I can make sure you feel they are accurate. This can be done in a number of ways and it will be entirely your decision how you receive the feedback and give your comments. If you wish I can post the feedback on a web page that I will set up. You could then view the feedback and email me your comments. Alternatively I could post you a copy of the written feedback and you could post back your comments or I could arrange to telephone you. Please note however, if you choose to respond via email whilst I will do everything possible to ensure your responses remain confidential there is the risk that other internet users could gain access to your email and may be able to identify you.

Will my taking part in this study be kept confidential?

All information collected about you during the course of this research will be kept strictly confidential. If your interview is tape recorded the tapes will be destroyed six weeks after they have been transcribed. All information about you will have your name and address removed so that you cannot be recognised from it. All data will be stored in locked cabinets on secure premises and I will be the only person with access to them.

What will happen to the results of the research study?

The data gathered will be used for publications in journals. However, it will not be possible to identify any participant in any report or publication. A copy of my final thesis will also be kept in the Liverpool John Moores University library.

Who is organising and funding this research?

Liverpool John Moores University

Contact for further information:

Joanne Hogan
70 Great Crosshall Street
Liverpool
L3 2AB

I would like to thank you for taking part in this study

Appendix 5: Parent information sheet



Parent Information Sheet

Name of researcher: Joanne Hogan

Supervisor: Dr Maureen Horgan

Title of study/project: Transition to adulthood for young people with Cystic Fibrosis

I would like to invite you to consent to your child taking part in the above study. Please take the time to read the following information and ask me if there is anything that is not clear or if you would like more information.

Thank you for reading this.

Purpose of study:

The purpose of this study is to look at the experience of the transition to adulthood and the things that affect this transition for young people with CF. This study will be based entirely on the perspective of young people with CF themselves, which I will gather through the use of interviews.

I would like to interview your child as we want to be able to understand their thoughts, feelings and opinions on the various processes of transition that young people their age encounter. I hope that by interviewing young people with CF we can begin to have a better understanding of the transition process for young people with CF and how the people around them and services they encounter affect this transition.

Throughout this study I will give young people with CF the opportunity to highlight areas that are important to them that have not previously been considered. I hope that this will allow young people with CF themselves to influence services in the future.

What will my child have to do?

I would like to conduct an interview with your child that will last around one and a half to two hours. I will arrange with your child a convenient time and place to carry out the interviews. Interviews can be conducted in a private room in the hospital or on university premises or in your home if your child prefers. With your child's permission I would like to tape record the interviews.

The interviews are to give your child the opportunity to express their thoughts, feelings and opinions about the transition to adulthood. They will be invited to talk about the following areas:

- Their experiences of the transition to adulthood including: the transition from school to training, further education or employment; the transition to financial independence; the transition to independent living and the transition from paediatric to adult care

- How they feel the people around them such as friends and family members influence this transition and their goals for the future
- How places such as hospitals and schools affect them during the move to adulthood
- Whether there are any other things that they feel influence the transition to adulthood
- Whether they feel there are any barriers within society that may hinder or prevent them in making this transition and achieving their goals for the future
- What changes they feel could be made in order to remove these barriers

Should the interview raise issues your child feels they want to discuss with someone other than the researcher, support will be available through the CF Department. If at any time throughout the study your child feels they need this extra support they can just let the researcher or any member of the CF team know.

With yours and your child's permission following the interview I would need to obtain some information from your child's medical records in order to see how they are affected by Cystic Fibrosis. This would be supplied by one of the medical/nursing team looking after your child. Please note that I will not at any time have access to your child's medical records.

Following the interview I will provide all participants with written feedback of the analysis I have made. It will not be possible to identify any participant from this feedback. I will then ask participants to give me their comments on the interpretations I have made so I can make sure they feel they are accurate. This can be done in a number of ways and it will be entirely your child's decision how they receive the feedback and give their comments. If they wish I can post the feedback on a web page that I will set up. They could then view the feedback and email me their comments. Alternatively I could post them a copy of the written feedback and they could

post back their comments or I could arrange to telephone them. Please note however, if they choose to respond via email whilst I will do everything possible to ensure their responses remain confidential there is the risk that other internet users could gain access to their email and may be able to identify them.

Will my child's participation be kept confidential?

All information collected about your child during the course of this research will be kept strictly confidential. If their interviews are tape recorded the tapes will be destroyed six weeks after they have been transcribed. All information about your child will have their name and address removed so that they cannot be recognised from it. All data will be stored in locked cabinets on secure premises and I will be the only person with access to them.

What will happen to the results of the research study?

The data gathered will be used for publications in journals. However, it will not be possible to identify any participant in any report or publication. A copy of my final thesis will also be kept in the Liverpool John Moores University library.

Who is organising and funding this research?

Liverpool John Moores University

Contact for further information

Joanne Hogan

70 Great Crosshall Street

Liverpool

L3 2AB

Appendix 6: Initial interview topics

Participants will be invited to talk around the following areas:

- Their experiences so far of the transition to adulthood including: the transition from school to training, further education or employment; the transition to financial independence; the transition to independent living and the transition from pediatric to adult care
- Their aspirations for adult life
- How they feel family members and friends impact on this transition
- How the settings they encounter (e.g. school and hospital) impact on this transition
- What other factors if any impact on the transition to adulthood and their aspirations
- The barriers within society they feel may hinder or prevent them from successfully negotiating this transition and achieving their aspirations
- The changes they feel are necessary in order to remove these barriers

Appendix 7: Example of participant feedback



Dear

Re: The transition to adulthood for young people study

Firstly, I would like to thank you again for taking part in the above study. As we discussed in the interview I would like to give you some feedback on your interview. Below is a short summary of the things you spoke about that I felt were most important to you.

- You spoke about looking forward to making the transition to adult care and you had received a lot of preparation for moving there. You thought you would be going for a visit to the adult clinic soon. You said you would miss the staff at but you felt that going to the adult clinic was important as it was all part of becoming an adult.
- You said that you had the responsibility for your own health care and this was very important to you. This was something that your parents had helped you to do over the last few years.
- You said that you always do your treatments and you felt it was really important to do so. You did not find it a struggle to do all of your treatments as they were just a part of your daily routine. You felt it was important to do the treatments to keep yourself as well as possible.

- You thought that going to university, moving out one day, getting married and having children were all part of the transition to adulthood and these are all things you hope to achieve in the future. You said that you might need some extra support to achieve these things but that your parents would support you.
- You said that you would only tell friends about your CF if you trusted them. You had never experienced a negative reaction from anyone but felt this was because you were very careful about who you told.
- You did not like the way CF was shown within the media. You felt it was very negative and this might make people think that people with CF are always ill. Sometimes your friends became upset when they saw things on the TV and then you would have to comfort them and explain it's not like that for everyone.
- You said that you could talk to your family about the CF. You also got on very well with the CF nurse specialists and felt you could go to them with any worries.
- You thought that people with CF may encounter barriers in making the transition to adulthood but that it was up to the individual to remain positive and be optimistic.

I would appreciate it if you could give me any thoughts you have on the attached form. I have enclosed a stamped address envelope for to return the form to me. If I don't hear from you then I will assume that you have agreed with the things I have said.

Thanks again,

Joanne.

Feedback Form for

If there is not enough space for any of your answers then just continue them on a separate sheet of paper

Did you agree with the things I have said?

If no what did you not agree with?

.....
.....
.....
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Do you think I have missed anything out that was important to you and if so what are these things?

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Appendix 8: Assent form



ASSENT FORM

TRANSITION TO ADULTHOOD FOR YOUNG PEOPLE WITH CYSTIC FIBROSIS

Investigator name: Joanne Hogan

- **I have read the information sheet and understand that I can ask Joanne for further information if I need it.**
- **I understand that if I want to I can decide not to carry on taking part without giving a reason and know that I will still receive the best possible treatment**

Name of patient (Please Print)

Signature

Date



INVESTOR IN PEOPLE

Appendix 9: Parental consent form

RESEARCH CONSENT FORM

To be completed by parent/person with parental responsibility

Title of study:.....
.....

Name of Investigator:

Permission is given for to be included in the above titled study.
(please print)

- I confirm that the above study has been fully explained to me
- I was given opportunity for further explanation by the investigator
- I have received a copy of the parent information document

Participation in this study is entirely voluntary and there is a right to withdraw from the study without giving a reason and in the knowledge that treatment following withdrawal will not be affected.

Name of parent/person with parental responsibility
(please print)

Signature.....

Signed in the presence of.....
as witness to the above signature. *(please print)*

Signature of witness Date

Job title and department if member of staff

Address if unconnected with the hospital

..... Post Code

Top Copy - To be retained in Medical Care Notes
Yellow Copy - To be retained by parent/person with parental responsibility
Green Copy - To be retained by the investigator



Appendix 10: Consent form

Study Number: 713

CONSENT FORM

Title of Project: Transition to adulthood for young people with Cystic Fibrosis

Name of Researcher Mrs Joanne Hogan

Please initial box

1. I confirm that I have read and understand the information sheet dated 4th June 2006 for the above study.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from the Cardio-thoracic Centre. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Joanne Hogan
Researcher

29/8/06
Date

[Signature]
Signature

1 copy for patient, 1 copy for research, 1 copy to be kept with hospital notes

Version 1.0, dated 15.03.05