

**EDUCATION AND EMPLOYMENT: THE BELIEFS, ASPIRATIONS AND  
EXPERIENCES OF YOUNG PEOPLE WITH CYSTIC FIBROSIS: A  
QUALITATIVE STUDY**

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The candidate confirms that the work submitted is her own and that appropriate credit  
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## ABSTRACT

This research explores the educational and employment experiences of young people with Cystic Fibrosis (CF) and was carried out as two separate studies. Study one consists of a small-scale survey examining the educational and employment history of 162 patients attending the Leeds regional Adult CF centre. Analysis of the data was conducted using non-parametric (Spearman's) correlations, t-tests and logistic regressions. Study two consists of qualitative analysis of interviews with six young people with CF discussing educational and employment experiences and their understanding of the factors that influenced the development and attainment of aspirations. Using Grounded Theory (GT) methodology, an overall theoretical model of participants' experiences has been developed, providing some speculations as to why many do not fulfil their potential.

Study one found the educational attainment and employment of people with CF to be lower than those in the general population (OECD, 2011; 2008). Socioeconomic status was the factor most predictive of school leaving age, educational attainment at degree level and perceived impact of CF on education and career and disease severity and educational level the factors most predictive of employment. Findings from study two revealed several themes: physical and practical consequences of CF and in some cases the actions of others, illustrated many practical and prejudicial barriers that prevented many from attaining their educational and occupational aspirations. The reality of struggles to achieve and maintain educational and occupational performance because of CF, and worries about their health and life expectancy had a significant impact on self-belief and belief in educational and workplace providers. This lowered expectations of achieving educational and occupational success, resulting in a withdrawal from aspirations and subsequent educational and occupational attainment. It is hoped that the findings of this study will contribute to the wider CF literature and that of other chronic illnesses and disability.

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**ABBREVIATIONS**

BCS70: British Cohort Study 1970

BMI: Body Mass Index

CF: Cystic Fibrosis

CFTR: Cystic Fibrosis Transmembrane Conductance Regulator

DLA: Disability Living Allowance

FEV<sub>1</sub>: Forced Expiratory Volume in one second

GRT: Gene Replacement Therapy

GT: Grounded Theory

HHI-N: Herth Hope Index-Norway

IMD: Index of Multiple Deprivation rank

IPA: Interpretative Phenomenological Analysis

NVQ: National Vocational Qualifications

YCS: Youth Cohort Study 1980

## CHAPTER I

## INTRODUCTION

**Cystic Fibrosis: Aetiology, Epidemiology and Treatment**

Cystic Fibrosis (CF) is a complex long-term health condition which predominantly affects the respiratory and digestive systems within the body. It is a progressive genetic condition caused by mutations on chromosome seven, which leads to abnormalities in the production and function of a protein called the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) (Conway, Brownlee, Peckham, Lee & Etherington, 2008). In the body, inactive or inefficient functioning of the CFTR results in impaired chloride and sodium transport and increased salt content in sweat gland secretions (Conway et al., 2008). This causes mucus in the respiratory tract to become abnormally sticky and open to infection leading to severe lung damage and respiratory failure (NICE, 2010; Walters & Warren, 2001). In the digestive system, this can cause the pancreas to produce insufficient amounts of enzymes needed to digest food; leading to malabsorption, vitamin deficiency, weight loss and severe ill health (Walters & Warren, 2001). In addition, CF can also lead to arthritis, male infertility, diabetes, liver and renal problems (NICE, 2010).

Approximately one in 25 of the population carries the defective gene causing Cystic Fibrosis (Cystic Fibrosis Trust, 2010). For a child to be born with CF both parents must be carriers; in these circumstances a child has a one in two chance of carrying the defective gene and a one in four chance of being born with the disease (Cystic Fibrosis Trust, 2010). It is estimated today that 70,000 people worldwide have CF; in the UK alone, one in 2,500 children are born with the disease. Although CF affects individuals of most racial and ethnic backgrounds, it is one of the most common, life-threatening inherited diseases among Caucasians (Grieve, Tluczek, Racine-Gilles, Laxova, Albers & Farrell, 2011; Walters, Britton & Hodson, 1993).

As yet, there is no cure for CF (NICE, 2010). Essentially, treatment aims to maintain the health of patients by targeting the symptoms of the disease as they occur (Lowton & Gabe, 2003). This can involve a daily regime of oral, intravenous or nebulised antibiotics, chest physiotherapy and exercise, plus pancreatic enzyme supplements and high calorie diets (Walters & Warren, 2001). A potential new treatment of medical interest is gene replacement therapy (GRT); though, this is still in the relatively early stages of development (Lowton & Gabe, 2003). As pulmonary function deteriorates, the end of the therapeutic range for many patients is lung or heart and lung

transplant (Walters & Warren, 2001; Bakker, 2007). However, this is not the ideal solution for many patients and sadly it is still the case that nearly all patients with CF die from pulmonary difficulties (Bakker, 2007).

### **The Changing Outlook**

Cystic Fibrosis was first identified as a disease in the 1930's, during which time 70% of patients died before their first birthday (Anderson, 1938). Today, CF is recognised as a spectrum of disease, sub classified as 'typical' or 'atypical' disease (Lowenfels & Simmonds, 2010). 'Typical' disease is a diagnosis in childhood and is currently the most common type of CF diagnosed. 'Atypical' CF is a diagnosis late in life, usually representing a milder course of the disease (Simmonds, Cullinan & Hodson, 2009). Over the past few decades, rates of survival have dramatically increased and CF, once a fatal diagnosis of infants, is now a chronic disease of children, adolescents and adults (Demars, Uluer & Sawicki, 2011). In the UK and other industrialised countries, childhood death from CF is now rare and children born in the UK today will now enter adulthood with a median predicted survival of 41.4 years (Cystic Fibrosis Trust, 2012a).

#### ***Factors relating to longevity in CF***

Improvement in the survival of people with CF first began during the 1980s and has continued to rise (Lowenfels & Simmonds, 2010). There has been some evidence to suggest good nutritional status in children with CF positively correlates with CF survival in adulthood (Mahadeva, Webb, Westerbeek, Carroll, Dodd, Bilton et al., 1998). As is widely reported in the chronic illness literature, there is also evidence to suggest environmental factors such as socioeconomic status play a part. In particular, rates of survival have been found to be higher in people from higher socioeconomic backgrounds; one explanation is that this decreases a person's exposure to detrimental factors such as smoking (Schechter, 2003). The majority of the literature however, indicates improved survival rates as largely the consequence of earlier diagnosis and better medical care. With the development of CF treatment centres, it has been possible for frequent surveillance and antibiotics and lung clearance measures to be implemented as standard practice for people with CF, hugely increasing survival rates (Hodson, Simmonds, Warwick, Tullis, Castellani, Assael et al., 2008). Medical advances in CF-related pharmacology, in particular, treatment with nebulised antibiotic Tobramycin or oral Azithromycin have been found to greatly improve pulmonary function. Specifically, Tobramycin has been found to reduce the total number of antibiotic treatments and hospital admissions (Bakker, 2007).

Evidence suggests that a diagnosis of CF late in life is a common characteristic of many long-term survivors. With little research distinguishing between early and late diagnosis, there has been some debate in the literature that survival rates may be getting skewed by the latter (Rodman, Polis, Heltshe, Sontag, Chacon, Rodman et al., 2005). However, in a UK study of 112 patients reaching 40 years of age, a high proportion of patients were found to have features indicative of ‘typical’ CF e.g. 82% were pancreatic insufficient and 68% had been diagnosed before their 16<sup>th</sup> birthday (Simmonds et al., 2009). These findings indicate people with ‘typical’ CF disease are reaching long term survival, suggesting survival rates may not be as skewed as some predict. Of particular interest, 30% of participants were found to be homozygous for the most severe CF mutation, *delta F508* (Simmonds et al., 2009). This finding has also been confirmed by an international study conducted by Hodson et al. (2008) and more recently by Lowenfels and Simmonds (2010). These findings illustrate that the type of CFTR mutation, once thought to be a crucial factor in determining survival, is in fact a poor predictor. In essence, people with CF, even with the presence of the most severe mutation are still achieving long-term survival (Hodson et al., 2008). Interestingly, both these studies found the pulmonary function and Body Mass Index (BMI) of people with CF to stabilise after the age of 40 years thus, improved pulmonary function and BMI have also been associated with an increase in survival rates (Hodson et al., 2008; Lowenfels & Simmonds, 2010).

In summary, evidence shows an increasing number of people with characteristics indicative of both ‘atypical’ and ‘typical’ CF are now reaching adulthood with reasonable BMI and lung function. In the present climate it is estimated that larger proportions of people with CF will now reach retirement due to old age, rather than ill health (Simmonds et al., 2009). Whilst there may be an array of causal factors, it seems likely that the increase in CF survival rates is predominantly the consequence of medical advances in treatment. However, findings must be interpreted with caution. Due to the paucity of research into adult survivors of CF, it is difficult to say whether findings are isolated to the specific CF centres or generalisable to the wider population. Trying to gauge which people will become long-term survivors therefore continues to prove a challenge for many within the field (Lowenfels & Simmonds, 2010).

## **Educational and Occupational Attainment in CF**

With increased longevity the attainment of age-related developmental tasks is now an important and achievable part of life. People with CF are now able to attend school, obtain qualifications and enter the labour market (Havermans, Colpaert, Vanharen & Dupont, 2009). Achieving such tasks however, coexists with challenges in increasing self-care, primarily, adherence to a demanding treatment regimen and coping with the progression of the disease (Besier & Goldbeck, 2011). The impact of this upon educational and occupational attainment is becoming a major topic of interest. This next section reviews the evidence.

### ***Findings from the UK***

A survey of 866 people with CF, 16 years and older, conducted in the UK in the early 1990s showed fewer left school with formal qualifications than in the general population (11% versus 15%) and fewer were in paid employment (54% versus 69%) (Walters et al., 1993). In the years following this survey, a number of health, educational and social service reforms took place across the UK. Recognising that these changes may potentially benefit or disadvantage the adult CF population, a larger UK survey examining the social and demographic characteristics of 1245 adults with CF was carried out in 2001 (Walters & Warren, 2001). Compared with figures from the 1993 survey, an increase was found in the attainment of higher qualifications and A-levels of people with CF. In contrast to the earlier findings of Walters et al. (1993), the educational attainment of people with CF was found to be similar (possibly better) than that of the general population (Walters & Warren, 2001). Occupational attainment however, illustrated a slightly bleaker outlook. Compared with the figures from the 1993 survey, the employment rates in 2001 had fallen by 7%. Only 47% of participants were found to be in paid employment; significantly lower at all ages than those in the general population, except for those aged 50 and older. This was particularly evident for the younger people in the sample (Walters & Warren, 2001).

In 2004, figures from the UK CF Registry illustrated a further fall in employment rates. From a sample of 2827 people with CF only 48% were found to be in employment; 36% working fulltime and 12% part time. A total of 789 (28%) were found to be unemployed (Cystic Fibrosis Trust, 2004a). Two recent UK surveys further support these findings. A survey of 100 adults, 55% male, mean age 28 years was conducted at the West Midlands Adult CF Centre in Birmingham between June and July 2011. Fifty-two per cent of participants were reported as being in full or part-time employment; 14% studying full or part-time and 34% were neither employed nor in

education (Nash, Kavanagh, Williams, Bikmalla, Gray & Whitehouse, 2011). Similarly, a survey of 92 adults, 48% female, mean age 28 years (range 18 to 66 years) was conducted at the Liverpool Heart and Chest Hospital. Thirty-seven (40%) participants were reported as being in full or part-time employment (49% versus 51%) and 37% were unemployed. In terms of educational attainment, 28 participants had obtained GCSEs; 14 participants had obtained A-levels; and 20 attended college. Only 16% of participants had obtained a university degree, this is less than the figure for the general UK population, which has been between 35-39% since 2000 (Huq, Sureshkumar, Kalidindi, Harris, Greenwood & Ledson, 2011; OECD, 2011). Comparing the recent findings on occupational attainment from Nash et al. (2011) and Huq et al. (2011) with that of the general UK population, evidence also suggests people with CF have lower occupational attainment than those in the general population, which for all 16 to 64 years is 70.4% (OECD, 2008). Overall, figures from the UK CF Registry (based on 2010 data) showed only 70% of people over the age of 16 with CF to be actively engaged in some sort of education or work (Cystic Fibrosis Trust, 2012a).

#### ***International findings: comparison with the UK***

Studies conducted in CF populations in a number of other countries are consistent with the rates of employment found in the UK: 56% of 130 participants in Canada were reported to be in employment (Frangolias, Holloway, Vedel & Wilcox, 2003); 55% of 49 and 48% of 183 participants in California and North Carolina respectively (Gillen, Lallas, Brown, Yelin & Blanc, 1995; Burker, Sedway & Carone, 2004); 72% of 50 participants in Australia (Hogg, Braithwaite, Bailey, Kotsimbos & Wilson, 2007); 55% of 670 participants in Germany (Besier & Goldbeck, 2011) and 70% of 207 participants in France were reported to be in employment (Laborde-Castérot, Donnay, Chapron, Burgel, Kanaan, Honoré et al., 2012). To date, the largest CF cohort in which both educational and occupational attainments have been surveyed is that of Laborde-Castérot and colleagues in France. Interestingly, out of the 70% who reported they were in employment, 25% were in professional occupations; 39% Intermediate; and only 4% were blue collar workers. These findings support that of Burker, Trombley, Sedway, Parker Yeatts and Carone (2005) who found 73% of those employed in their CF cohort were in skilled professions. These findings suggest therefore that those who do secure employment are more likely to be working in skilled professions than unskilled. This however, may be explained by the educational level of the cohort. Similar to the UK study by Walters & Warren (2001), the educational level of the French CF cohort was found to be higher than that of the general population, with 72% of participants having obtained a high school diploma; 57% studied at least 2 years

at university; and 17% having obtained a masters degree (Laborde-Castérot et al., 2012). The dominance of people with CF working in skilled professions therefore, may be the consequence of higher educational attainment.

### ***Limitations of the current evidence base***

There are a number of limitations which need to be addressed when evaluating and interpreting the current evidence. Firstly, the surveys differed in terms of their sample size. Although not explicitly reported, they may also have differed in terms of their response rates. These methodological differences may have skewed reported findings. Furthermore, most surveys were carried out as single-centre studies and few reported the employment status of those who didn't take part. Thus, it may be that people who were unemployed had more opportunity to complete the survey, therefore skewing reported unemployment rates (Walters & Warren, 2001; Laborde-Castérot et al., 2012). A potential survivor effect may have also biased findings. Few studies distinguished between early and late diagnosis; those with late diagnosis therefore may have had less severe disease potentially skewing employment rates (Besier & Goldbeck, 2011).

To complete the surveys there was also a need for participants to have basic literacy skills. There is a possibility therefore, that samples are biased in favour of those with higher educational and socioeconomic status. For example, whilst the increased levels of education found in the 2001 UK survey might have been the consequence of educational reform i.e. initiatives from the government to encourage young people to carry on in education; this may also have been the consequence of responder bias (Walters & Warren, 2001). Furthermore, although most studies collected data on social economic circumstance, no study examined the relationship between socioeconomic status and educational and occupational attainment. Finally, due to the ongoing medical advances in treatment, what little research there is, can quickly become out of date. With these issues in mind, the present findings should be interpreted with caution.

### **Summary**

In reviewing the limited research on the educational attainments of people with CF, the findings appear conflicting. Where the findings from UK surveys by Walters et al. (1993) and Huq et al. (2011) suggest impaired educational attainment of young people with CF, the UK survey by Walters and Warren (2001) and that of the French cohort by Laborde-Castérot et al. (2012) found the educational attainment to be similar (possibly better) than the national averages. In contrast, research into the occupational attainments of people with CF in the UK and other countries is undisputed. In the UK

alone, although fluctuating, evidence indicates that people with CF are significantly less likely to be in employment than people in the general population, of the same age and sex (Walters and Warren, 2001; Huq et al., 2011).

In summary, there seems to be a weak association between people with CF surviving and educational and occupational attainment increasing, though coverage is limited. Although young people with CF may attain the levels of education equivalent to the general population, they do not appear to achieve the occupational outcomes medical advances in treatment now allow.

### **Achievement Treatment Gap: Factors Predicting Educational and Workplace Participation of People with CF**

Despite the growing importance and significance of quality of life, there is limited research investigating the educational and workplace participation of people with CF (Hogg et al., 2007). This next section reviews the evidence.

#### ***Disease severity***

Much of the research carried out to date on educational and workplace participation of people with CF has adopted an ‘illness focused’ epistemological stance (Edwards & Boxall, 2010). The current literature has focussed on ‘disease severity’ as the main determinant of educational and occupational outcome. Evidence suggests that people who have more severe CF disease are less likely to achieve educational qualifications or be in employment (Walters et al., 1993; Havermans et al., 2009). In particular, non-working people with CF have been found to have significantly lower lung function, more often have *Pseudomonas aeruginosa* and take more high caloric supplements than people who are working (Havermans et al., 2009). Although lung transplantation has been found to be associated with improved workplace participation in people with CF, frequencies of CF hospital admissions have been found to be the best indicator of hours worked and occupational decision-making (Cicutto, Braidy, Moloney, Hutcheon, Holness & Downey, 2004; Hogg et al., 2007). However, not all clinical parameters of disease severity have been found to be good predictors. Of particular interest, Burker et al. (2004) found no difference in FEV<sub>1</sub> (forced expiratory volume in one second) levels between employed and unemployed people with CF. Interestingly, Laborde-Castérot and colleagues in France did find FEV<sub>1</sub> to be statistically significantly associated with employment status, however this was not found to strengthen as lung function decreased. Risk therefore does not appear to increase linearly as lung function

deteriorates, further compounding doubt that FEV<sub>1</sub> is a valid predictor of work disability (Laborde-Castérot et al., 2012).

### ***Treatment adherence***

The daily treatment regimen for people with CF can be a burden. For some, this can take up to 2 hrs a day and as severity of CF disease increases, sometimes longer. Trying to maintain treatment adherence can be problematic when in employment. In the French CF cohort, 71% of participants who reported receiving at least one antibiotic treatment in the last year stopped working during their treatment. However, daily time spent on treatment was not found to affect work status (Laborde-Castérot et al., 2012). This may be explained by those who required higher levels of treatment adjusting their working hours accordingly so as to maintain their treatment regimen (Laborde-Castérot et al., 2012). Interestingly, in an American CF cohort of 68 employed individuals, aged 16 to 25 years, the majority (79%) reported they did not complete their treatment at work. Only 32% reported forgetting to take medication 'at least occasionally' due to their work commitments (Demars et al., 2011). Somewhat surprisingly, these findings suggest treatment is neither a barrier to employment nor employment a barrier to treatment. However, findings should be interpreted with caution, as this may be the consequence of a high percentage of participants being in part-time employment and therefore working their treatment around work. Alternatively this may be an over-reporting of adherence rates (Demars et al., 2011).

There is some evidence to suggest adherence to treatment can be problematic for workplace participation, however to substantiate findings, further research must be conducted.

Since 1993, the proportion of people with CF not in employment as a consequence of ill health has fallen, yet rates of unemployment remain high (Walters & Warren, 2001). Whilst this may be explained in part by an increase in people studying, it has become apparent that whether a person with CF is working is not solely related to their medical status (Walters & Warren, 2001). This next section reviews this evidence.

### ***Age***

A consistent finding within the CF literature is that the older an individual is the greater the number of hours they are likely to have worked (Gillen et al., 1995; Hogg et al., 2007). Whilst this may be in response to increased confidence in health management or increased financial commitments, it seems the younger an individual is, the less likely they are to be employed (Walters & Warren, 2001; Hogg et al., 2007). This may also be

explained by an increased likelihood that younger people are in education. However, not all research has found this relationship; work status was found to be unaffected by age in the French CF cohort (Laborde-Castérot et al., 2012).

### ***Sex***

Female sex has also been reported as an independent risk factor for CF work disability (Burker et al., 2004). Significantly more females than males (23% versus 13%) were reported to be neither employed nor in education in a UK CF cohort (Nash et al., 2011). It is important to note that no data was collected on childcare duties and this therefore may account for the lower number of females in employment or education. Not all studies have found this relationship however, in the French CF cohort work status was found to be unaffected by sex (Laborde-Castérot et al., 2012).

### ***Socioeconomic status***

Differences in socioeconomic status have also been implicated as determinants of CF educational and workplace participation. Evidence indicates people from manual social class backgrounds are less likely to leave school with educational qualifications and be in employment (Walters et al., 1993; Walters & Warren, 2001).

### ***Access to social service benefits***

Despite the improving prognosis, many people with CF are eligible to claim for a variety of government funded social security benefits. Evidence from two recent UK surveys found almost all patients currently claimed one or more benefit: 96% (Nash et al., 2011); 83% (Huq et al., 2011). The most common received was Disability Living Allowance (DLA): 91% (Nash et al., 2011); 89% (Huq et al., 2011). Despite the majority of the CF population receiving benefits, little association has been found with the level of disability (Nazareth, Tan, Abdul, Jordan, Greenwood, Ledson & Walshaw, 2010). It may be therefore that access to such support is reducing an individual's incentive to engage in employment (Morris, 1999).

### ***Prevalence of depression***

Prevalence of depression within the population of CF varies. There is some research which suggest people with CF have lower rates of depression than in the general population (Blair, Cull & Freeman, 1994); whereas some report prevalence to be higher (Crews, Jefferson, Broshek, Barth & Robbins, 2000), a finding supported by the recent TIDES international study of rates of depression and anxiety in people with CF (Quittner, 2012). Rates of depression have been found to be an independent risk factor

for CF work disability (Burker et al., 2004). Those who are depressed may experience psychomotor slowing and reduced concentration and motivation, all of which can also adversely affect educational performance (Fröjd, Nissinen, Pelkonen, Marttunen, Koivisto & Kaltiala-Heino, 2008).

### ***Level of educational attainment***

One of the main determinants of people with CF obtaining employment is educational attainment. In particular, GCSEs or A Levels have been found to be associated with enhanced rates of employment (Walters & Warren, 2001). This finding is confirmed by the French CF cohort, which found educational level was the factor most predictive of employment in people with CF (Laborde-Castérot et al., 2012).

Despite the majority of the literature implicating ‘disease severity’ as the main determinant of CF educational and workplace participation, there is in fact evidence to suggest factors such as age, sex, socioeconomic status, access to benefits, prevalence of depression and (especially) level of educational attainment also play a role. With the majority of published research adopting an ‘illness focussed’ epistemological stance, very little research has explored the views, experiences and understandings of educational and workplace participation in people with CF. However, the little research there is indicates a number of individual, prejudicial and environmental barriers faced by people with CF. This next section reviews this evidence.

### ***Experience of CF in the school environment***

Mild CF disease is often experienced in early childhood; however during adolescence an increase in disease severity is frequently observed (D’Auria, Christian, Henderson & Haynes, 2000). This can cause a number of difficulties and interruptions for an individual in school. An American qualitative study investigating the influence of peer relationships on adjustment to CF in adolescence explored this issue further. Participants reported ‘being out of the loop’ as an increase in disease severity disrupted peer relationships, school attendance and ability to keep up with school work. They described how when they returned to school they often felt ‘out of place’ (D’Auria et al., 2000). Several participants discussed how the physical limitations of CF were not understood by peers and staff in school as many of the symptoms ‘you can’t see.’ A lack of understanding and ability of others to identify with these experiences often led participants to avoid talking about their CF (D’Auria et al., 2000).

Some of the highest rates of school absenteeism are in children with CF and it is little surprise that rate of absence has been found to be negatively associated with

educational performance (Fowler, Johnson, & Atkinson, 1985; Grieve et al., 2011). In some cases, severity of CF disease has caused many to drop out of school (D'Auria et al., 2000). Eighteen (13%) participants in the French CF cohort reported stopping their studies because of CF (Laborde-Castérot et al., 2012). This is extremely worrying considering it is the school setting which not only hones educational attainment, but fosters ones sense of belonging and identity (Sroufe, Cooper & DeHart, 1996).

### *Attitude towards school*

Individuals with CF, as discussed, can face many challenges at school. These experiences can positively or negatively influence their attitude towards school, which in turn has been shown to have important implications for educational success (Grieve et al., 2011). Of interest, low self appraisal of educational performance (Heaven & Newbury, 2004); low educational aspiration (Abu-Hilal, 2000) and increased risk of school drop-out (Croll, Attwood, Fuller & Last, 2008) have all been found to be associated with negative school attitude. Interestingly, males have been found to be at greater risk for school dissatisfaction than females (Grieve et al., 2011).

### *Self-efficacy*

Degree of self-efficacy has also been found to be influential in educational settings. Self-efficacy is defined as “belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations” (Bandura, 1995, pp. 2). In essence, this is belief in one’s own ability to succeed. Self-efficacy has been found to be associated with better educational performance (Bassi, Steca, Fave & Caprara, 2007); and higher career aspirations (Bandura, Barbaranelli, Caprara & Pastorelli, 2001). In an American study of 40 adolescents aged 16 to 21 years with CF, self-efficacy was found to be a crucial determinant of educational performance and achievement. Relationships with teachers and peers were essential for enhancing feelings of success and those who reported stronger beliefs in their abilities experienced fewer depressive symptoms (Grieve et al., 2011). Interestingly, the relationship between self-efficacy and educational performance is bidirectional; whilst mastery and success experienced in school can influence general feelings of self-efficacy, self-efficacy developed from life experience can also influence educational performance (Grieve et al., 2011).

Degree of self-efficacy may be influential in overcoming the numerous challenges and barriers faced by people with CF in educational settings. Such findings however, should be interpreted with caution, as the sample size was small and it may be that those who chose to take part were functioning better (Grieve et al., 2011). Self-efficacy however, has also been found to be a powerful predictor of workplace

participation and quality of life in people with CF; therefore it is likely a relationship between self-efficacy and attainment does exist (Goldberg, Iralsky & Schwachman, 1985; Wahl, Rustøen, Hanestad, Gjengel & Moum, 2005).

### *Disease mastery*

In people with CF a relationship has also been found between the hours a person works and their perceptions of disability and quality of life, defined as ‘disease mastery’ (Hogg et al., 2007). Research shows that young people who feel more in control of their disease and who are less fatalistic in their outlook are more likely to succeed in staying on in education or gaining employment (Banks, Bates, Breakwell, Bynner, Emler, Jamieson, & Roberts, 1992).

### *Hope*

Hope can be understood as the process by which the present is integrated with the future (Leifer, 1996). For young people with CF maintenance of a positive outlook is crucial (D’Auria et al., 2011). In a Norwegian sample of 86 adults with CF, 52% male, mean age 29 years (range 18 to 54 years), level of hope was measured using the Herth Hope Index (HHI-N) (Herth, 1992) and compared with that of the general population (Rustøen, Wahl, Hanestad, Gjengedal & Moum, 2004). People with CF were found to have slightly lower levels of hope than in the general population and significantly higher scores on the items ‘scared to think about the future’ and ‘deep inner strength’ (Rustøen et al., 2004). Whilst the former is not particularly surprising considering the progressive nature of CF, the item ‘deep inner strength’ is of interest. This item measured participants’ experiences of chronic disease as leading to a rethinking about what is important in life or a redefining of values (Sprangers, 2002). It may be therefore that lower educational and occupational attainment is the consequence of people choosing to spend their time on things other than education and work, due to fears that their future is limited (Rustøen et al., 2004). Interestingly, levels of hope were found to increase with age in people with CF, whilst those in the general population decreased. It may be that these participants at birth were not expected to survive to adulthood and have lived with uncertainty about their life expectancy much of their life. Reaching adulthood therefore, may feel like they have beaten the odds, giving them increased belief and hope in the future (Rustøen et al., 2004). Despite a high response rate, the sample size remains small; therefore findings should be interpreted with caution.

This literature, although limited, also illustrates a number of prejudicial attitudes and environmental barriers which people with CF can face when trying to secure and maintain employment (Edwards & Boxall, 2010).

### *Experience of CF and workplace participation*

A UK study investigating the employment experiences of 33 participants with CF, 51% male, mean age 25.9 years (range 17 to 53 years) identified 3 main themes: Career changes (19/33); Discrimination (11/33); and Difficulty getting and keeping a job (11/33) (Langman & Brennan, 2008). Five participants reported changing their career due to CF, primarily because of attempts to avoid infections, and 11 participants reported experiences of discrimination, mainly because employers did not understand their condition. Difficulty getting and keeping work was also discussed by 11 participants and reported to be the consequence of CF-related absence (Langman & Brennan, 2008).

Edwards & Boxall (2010) examined these issues further by undertaking qualitative telephone interviews with 21 participants, 61% female, with CF. Findings suggest a common challenge often faced is finding employment opportunities that are flexible enough to accommodate their daily, time consuming treatment regimen. This proves difficult and people with CF have reported overt discrimination by their employers; specifically an overshadowing of their abilities and qualifications and in some cases the withdrawing of job offers once employers were informed of their CF (Edwards & Boxall, 2010). Interestingly, people who did not reveal at interview that they had CF were more likely to be in employment. Sadly, revealing such a diagnosis appeared to place the individual at a disadvantage (Walters et al., 1993; Walters & Warren, 2001).

More recently, an American study assessed the current employment experiences and perceptions of the impact of CF in 68 employed participants, 57% female, mean age 19.7 years (Demars et al., 2011). Twenty-two percent of participants, more females than males (41% versus 8%) reported CF had affected their choice to seek employment and 22% their choice of occupation. Forty-seven per cent of participants reported missing at least one day of work per month due to CF; this was reported by 31% to be problematic for their employers and 22% reported stopping work altogether (Demars et al., 2011). The older the participant the more hours they were likely to have worked and the more likely they were to have disclosed their CF, stopped work due to CF and discussed job related issues with a clinician (Demars et al., 2011). Over the previous 3 years, only 16% of participants reported having discussed job-related issues with a clinician.

The majority (63%) of participants disagreed with the statement 'CF impacts my chances of getting a job' though 41% agreed with the statement 'balancing employment and CF care is stressful.' Those who were older and who had increased disease severity were more likely to agree with these statements (Demars et al., 2011). These findings should be interpreted with caution however, as only those in employment were surveyed. It may be therefore that findings underestimate the impact of CF as those without employment may have worse disease preventing them from working (Demars et al., 2011).

Finally, 55% of participants in the French CF cohort reported feeling limited in their job because of CF, 37% attributed a lower income to CF and 67% reported it had prevented them from having a career. For those participants (28) who were not in employment, CF was cited as the reason (Laborde-Castérot et al., 2012).

### **Summary**

Evidence, although limited, suggests factors such as school attitude, degree of self-efficacy, disease mastery and hope may be influential in people with CF attaining their educational and occupational potential. In the school environment, it is apparent that people with CF have much to overcome. The work environment appears to be similar, with many feeling limited by their CF and in some cases having to change or give up work. Due to a lack of understanding of the condition, several have reported experience of prejudice and discrimination, leaving some feeling vulnerable and marginalised (Cystic Fibrosis Trust, 2012b).

Much of the research carried out to date has been conducted using quantitative methods, and by its very nature is somewhat restricted. There are relatively few qualitative studies which provide a true window into the lived educational and occupational experiences of people with CF. Only one study in the UK has examined the employment experiences of people with CF using qualitative methodology. However, this was carried out from a social model perspective i.e. society is seen as the main contributory factor in disabling people and data was collected via telephone interviews from people with CF, primarily in employment (Edwards & Boxall, 2010). Furthermore, the first author herself had a diagnosis of CF; whilst this was reported to be advantageous by participants due to her familiarity with CF, there was little reflection on how this might have biased findings. Reflexivity, a crucial aspect of qualitative research, appeared absent.

Thus far, CF research has focused upon the experiences of people in education and employment; few studies have examined the experiences of people who are neither studying nor employed. Little is known about why people with CF cannot or choose not

to study or work. Further still no study as yet has explored the educational and occupational experiences of people with CF together.

Despite the findings that people with CF are extremely motivated employees and actually have limited absences from work, the perception that they are not as capable in meeting the demands of a job as those in the general population, still prevails (Walters & Warren, 2001; Edwards & Boxall, 2010). To overcome these barriers, many people with CF find themselves taking on voluntary work as this provides the flexibility necessary for their essential treatment regimes. However, as a consequence, many people find themselves 'underemployed' (Edwards & Boxall, 2010). Evidence suggests that people with CF are not the only people to be 'underemployed'. Sadly, this category has also been found to be disproportionately occupied by many people with disabilities (Edwards & Boxall, 2010; Burchardt, 2000). This raises the question whether the trend of lower educational and occupational attainment in people with CF is apparent in young people with different types of chronic illness. This next section reviews this evidence.

### **Educational and Occupational Attainments of People with Different Types of Chronic Illness**

#### ***Diabetes mellitus***

A ten year follow-up of young people diagnosed with diabetes mellitus between the ages of nine and 16 years found no differences in the educational and occupational attainments between those with diabetes and those in the general population (Jacobsen, Hauser, Willet, Wolfsdorf, Dvorak, Herman & De Groot, 1997).

#### ***Juvenile rheumatoid arthritis***

In childhood survivors of juvenile rheumatoid arthritis, evidence has shown no differences in educational attainment when compared with age matched controls. However, as in people with CF, unemployment has been found to be higher in those with the chronic illness; 30% compared to 13% of controls (Peterson, Mason, Nelson, O'Fallon & Gabriel, 1997).

#### ***Renal disorder***

Similar to that of CF, childhood survivors of renal failure have been found to have lower levels of educational attainment compared with controls. Occupational attainment has also been found to be impaired. Compared with 75% of controls, only 53% of adulthood survivors were found to be in fulltime employment (Morton, Reynolds, Garralda, Prostlethwaite & Goh, 1994).

### ***Cancer***

In a recent large population based cohort of British childhood cancer survivors, performance at all stages of educational attainment was found to be worse than those in the general population (Lancashire, Frobisher, Reulen, Winter, Glaser & Hawkins, 2010). However, unlike adults with CF, survivors of childhood cancer appear to catch up with their peers in adulthood. Apart from the subgroup of survivors of CNS tumours and leukaemia, adult survivors of childhood cancer have been found to experience similar levels of employment to the general population. In particular, survivors of bone sarcomas were shown to experience higher levels of employment than that of the general population (Lancashire et al., 2010).

### **Summary**

In summary, childhood survivors of renal failure and cancer have been found to have lower levels of educational attainment than those in the general population. However, childhood survivors of diabetes mellitus and juvenile arthritis show no educational impairment. Like the literature on CF, much of the evidence indicates ‘disease severity’ as the main determinant of lower educational attainment. In essence, children diagnosed with cancer or renal disorder are more likely to be exposed to pervasive medical interventions; accruing more time spent in hospital and more time absent from school.

In adulthood the majority of childhood survivors of cancer have levels of occupational attainment similar to the general population (Eiser, 1998). Again, those with diabetes mellitus do not appear to differ from those in the general population. Whilst some have argued these findings might be explained by diabetes (in some way) having protective effects, others have argued this may be the consequence of reporting bias (Jacobsen et al., 1997; Gledhill, Rangel & Garralda, 2000). There is a need for caution, therefore, in interpreting these findings. In contrast, like those with CF, childhood survivors of juvenile arthritis and renal disorder have been found to have lower rates of employment compared with the general population. Again, ‘disease severity’, in particular persistent severe illness in adulthood has been implicated as the main determinant (Gledhill et al., 2000).

Overall, like people with CF, many adult survivors of chronic physical illness with an onset in childhood experience impaired educational and occupational attainment compared with the general population (Gledhill et al., 2000). A question raised is, why do childhood survivors of cancer catch up with their peers in adulthood and childhood survivors of arthritis, renal disorder and specifically, CF, lag behind? As yet, these questions largely remain unanswered.

Conducting research into the educational and occupational attainment of adults with chronic illness since childhood is fraught with difficulties. The heterogeneity of chronic illness severity and the many external and internal factors which may predispose or protect an individual against adverse events can prove extremely challenging (Gledhill et al., 2000). The nature of this type of research also lends itself to the possibility of responder bias. Moreover, due to the rate of medical advance in treatment, this type of research can quickly become outdated. These methodological difficulties may explain the variations in findings and should therefore be interpreted with caution.

A final criticism of this research is that the majority of the findings neglect the subjective experiences of people with chronic illness. Like the CF literature, the majority of the research takes an ‘illness focussed’ epistemological stance, with a focus on ‘disease severity’ as the main determinant of educational and occupational impairment. This led me to ask whether there is any literature which explores the educational and employment experiences of people with chronic illness and disability. This next section reviews the evidence.

### **Educational and Employment Experiences of People with Chronic illness and Disability**

The employment experiences of people with CF seem to resonate with those of other disabled people (Barnes & Mercer, 2005). Like people with CF, unemployment rates among people with disabilities are much higher than rates of unemployment in the general population (Lowton & Gabe, 2003). Similar to those with CF, evidence suggests a number of possible factors which influence occupational attainment, such as lower educational level, lack of support services and discrimination (Knapp, Perkins, Beecham, Dhanasiri & Rustin, 2008). There has also been some research, like that of Rustøen et al. (2004) which suggest chronic illness may change a person’s opinion about what is important in life (Cousens, Waters, Said & Stevens, 1988). Thus, lower rates of educational attainment and employment may be the consequence of altered personal life goals (Gledhill et al., 2000).

A further explanation for this trend, absent in the CF literature, is that disabled people are not always encouraged to see themselves as having valuable roles to play in adult society, which as a result, translates into unduly limited aspirations (Wilson, 2003). Research illustrates a number of factors that influence the formation of aspirations, specifically: social class; peer group, parental and teacher expectations; parent educational level and personal resilience (Furlong, 1992; Schoon and Parsons, 2002; Burchardt, 2005; Low, 1996). Aspirations are a critical ingredient in the achievement of

educational qualifications and subsequent occupational outcomes later in life (Burchardt, 2005). Is lower educational and occupational attainment in people with chronic illness and disability the consequence of limited aspirations?

**The Rising Aspirations of Young People With and Without a Disability: To What Extent are Aspirations Achieved?**

Analysing the data from the 1970 British Cohort Study (a nationally representative study of all children born in one week in 1970, followed up to their mid twenties) (BCS70) and the 1980s Youth Cohort Study (a nationally representative study of people of school-leaving age born in 1982-85 with follow-up at aged 18/19 years) (YCS), Burchardt (2005) compared the aspirations of young people with and without disabilities and the extent to which aspirations were achieved. The study focussed on disabled people with physical or sensory impairments and mental health problems.

*Aspirations*

At 16 years of age, there were no differences found between the aspirations of young people with or without a disability. The majority of young people aspired to stay on in education and pursue a professional occupation (Burchardt, 2005). Educational and occupational aspirations were strongly associated with parents' educational and social class background. Regardless of disability, young people were four times more likely to leave education at age sixteen if their parents lacked educational qualifications than those whose parents were educated to degree level (Burchardt, 2005). Young people who had a greater belief in their ability to shape their future were more likely to have higher aspirations. Motivation and outlook were also reported as important, especially for those with a disability (Burchardt, 2005).

*Aspirations and educational outcome*

At 16 years of age, only 62% of people with a disability were found to be in fulltime education, compared with 71% of their non disabled peers (Burchardt, 2005). At age 18 and 19, only half of the people with a disability achieved qualifications higher than National Vocational Qualifications (NVQ) level 1 or D grade at GCSE, compared with 72% of people without a disability. Overall, the educational attainment of two-fifths of young people with a disability was below their initial aspirations, compared with only a third of those without a disability (Burchardt, 2005).

### *Aspirations and occupational outcome*

Between 16 and 17 years of age, people with a disability were twice as likely to be out of work as those without a disability. At 18 and 19 years, people were three times and at age 26, four times more likely to be unemployed than those without a disability (Burchardt, 2005). At 26 years of age, occupational outcomes for 39% of people with a disability (compared with 28% of those without a disability) were below their initial occupational aspirations (Burchardt, 2005).

### **Summary**

Evidence shows that young people express similar aspirations for their future, regardless of whether they have a disability. Whilst it is apparent that many young people fall below their initial aspirations in early adulthood, the gap appears wider for those with disabilities. Sadly, evidence shows that the lack of fulfilment of educational and occupational ambition adversely impacts upon the confidence of young people with disabilities. Consequently, in early adulthood people with a disability were more likely to have higher malaise scores with little confidence or belief that they could bring any strengths to the labour market (Burchardt, 2005).

Like people with CF, people with disabilities have been found to experience a number of environmental barriers which have obstructed many from achieving the goals they aspired to (Burchardt, 2005). There is other literature however, which suggests parents and teachers may be unnecessarily underestimating the academic capabilities of young people with disabilities. For instance, evidence illustrates that some young people with disabilities have been discouraged from taking particular options at school or from pursuing vocational qualifications (Burchardt, 2005; Gray, 2002; Wilson, 2003). Whilst some parents of children with disabilities have been found to express a desire to encourage and enhance the aspirations of their children, evidence has shown they fear disappointment if aspirations rise above likely outcomes (Mitchell, 1999). It is apparent therefore, that exposure to the beliefs of other people and the surrounding environment, may play a role in lowering the aspirations of people with disabilities. Research shows that without self-belief and encouragement, educational qualifications and subsequent occupational outcome are all too likely not to be attained (Burchardt, 2005).

There is little reported in the literature on the development and attainment of aspirations in people with CF. There is some research which suggests children born with CF today have aspirations and hopes in line with their 'healthy' peers (Badlan, 2006). Similar to the findings reported in the disability literature however, young people with CF experience difficulty fulfilling these aspirations, specifically as the demands of CF and the restrictions placed on them by its requirements increase (Badlan, 2006). For

some, this can result in a ‘trade off’ between quantity and quality of life, leading to a reduction in self-care and adherence to treatment (Radley, 1994). With advances in modern medicine and increased survival, there is now real potential for people with CF to consider a future (Elbourn, Shale & Britton, 1991). For those in their late twenties and thirties the prospect of a future is new and for some, adjusting to this ‘extra’ time may be difficult as many may be scared to believe in it (Badlan, 2006).

In contemplating the present study, the author met with doctors from the Leeds regional Adult CF centre. Here she heard anecdotal accounts of how young people with CF, specifically young adults, do not seem to be achieving the benefits increased longevity should now provide. With little research in the CF literature to explain and understand this, findings from the disability literature previously discussed were reflected upon. Could it be that people with CF still hold a belief that they won’t reach adulthood? If so, is it possible a form of ‘learned helplessness’ is present in young people with CF, resulting in the development of limited aspirations, self-belief and overall lowered expectations? If so, is it this which is causing young people with CF to adopt passive roles in society and not achieve their educational and occupational potential? Alternatively, is it practical barriers in the education system and (especially) in the attitudes of employers which is limiting the opportunities of a new generation of young people with CF? To date, these important questions remain largely unanswered in the CF literature.

### **Overall Summary and Conclusions**

Over the past few decades rates of survival have dramatically increased and CF, once known as a disease of childhood, is now being acknowledged as a spectrum of disease with 95% of children now entering adulthood, with a median predicted survival of 41.4 years in the UK (Dodge & Lewis, 2005; Dodge, Lewis, Stanton & Wilsher, 2007; Lowenfels & Simmonds, 2010; Cystic Fibrosis Trust, 2012a). Although young people with CF may largely attain levels of education equivalent to the general population, they do not appear to achieve the occupational outcomes medical advances in treatment now allow.

To date, the majority of the research undertaken on educational attainment and workplace participation of people with CF has focused upon ‘disease severity’. However, there is some research to suggest educational attainment and workplace participation is not solely related to their medical status. Factors such as disease mastery, self-efficacy and environmental and attitudinal barriers may also play a role, though evidence remains limited.

From a review of the literature on chronic illness and disability, it appears people with CF are not alone in achieving lower educational and occupational outcomes. Interestingly, literature within the disability field implicates the formation of aspirations and the opportunities for translating these into reality as an important facet in educational and occupational outcome. Whilst this has not yet been investigated in CF, limited aspirations and beliefs may be the result of lowered expectations by young people with CF; potentially influencing current educational and occupational outcomes.

To date, an illness focussed epistemological stance prevails in the literature on educational and occupational outcomes in CF. Little research has investigated the educational and employment experiences of people with CF or their understandings, specifically the experiences of those not in education or employment (Edwards & Boxall, 2010). In particular, the development and formation of beliefs and aspirations, and the potential role they play in mediating educational and occupational outcomes is not known.

With people with CF now surviving into adulthood the issue of education and employment is becoming increasingly important. It has been recognised that educational attainment may enhance an individual's opportunity to work and work may serve as a distraction from the symptoms of CF; potentially protecting patients from psychological problems (Havermans et al., 2009; Burker et al., 2004). The current generation of adults with CF will have different experiences of illness, and potentially a different expectation of the possibilities of a career to those previously surveyed. This increasingly aging, though predominantly invisible population have valuable experiences and understandings which need to be heard.

### **Introducing the Current Study**

The current study explored the educational and employment experiences of young people with Cystic Fibrosis. The research was carried out as two separate studies in collaboration with a wider steering group of four doctors and the psychologists from the Leeds regional Adult Cystic Fibrosis Centre based at St James's' Hospital.

Study one consisted of a small-scale survey examining the educational qualifications and employment history of patients attending the Leeds regional Adult CF Centre. This contextual information was used to scope the background to Study two.

Study two consisted of qualitative analysis of transcriptions of interviews with six young people with CF discussing educational and employment experiences. Qualitative data were analysed using Grounded Theory (GT).

### **Research Question**

What are the educational and employment experiences of young people with Cystic Fibrosis?

**Research aim:** To explore young people's experiences of education and employment and their understanding of the factors that influenced the development and attainment of aspirations.

## CHAPTER II

### STUDY I: EDUCATION AND EMPLOYMENT SURVEY

#### SURVEY METHODOLOGY

##### Design

In order to place the qualitative study in context, a cross-sectional survey was undertaken in the Leeds regional Adult CF Centre focussed on educational qualifications and employment obtained by patients, by the author in collaboration with a doctor undertaking research for her MD.

##### Measures

Participants completed a 3-page questionnaire designed for the study which examined basic demographics, educational attainment, employment history, benefit status and participants' perceptions of the impact of their CF on their education and career, assessed using a 10 point scale (rating 0 'Not at All' to 10 'Great Extent') (Appendix A). For each participant medical records were reviewed to obtain current FEV<sub>1</sub>, BMI and postcode. Current FEV<sub>1</sub> was used as a surrogate marker of disease severity and postcode status was used to calculate Index of Multiple Deprivation (IMD) ranks as a marker of socioeconomic status (SES).

##### Procedure

Over an 8 week period all adult CF patients arriving in outpatients were approached to take part, and given an information sheet if they agreed (Appendix B). They were then given the questionnaire to complete. Medical records were then used to obtain current FEV<sub>1</sub>, BMI and postcode. Socioeconomic status for each participant was calculated by converting postcodes into Index of Multiple Deprivation (IMD) ranks (rank 1 most deprived to 32,482 least deprived). Following convention, participants were divided into deciles 1-10 indicating most to least deprived. All survey data was analysed using non-parametric (Spearman's) correlations, t-tests and logistic regressions using PASW Statistics 18.

##### Pilot Study

To test the feasibility, language and overall acceptability of the questionnaire, two separate pilots were conducted in January 2011 with two non CF adults known to the author. Two modifications were made to the questionnaire following feedback.

It was suggested by the second participant in the pilot that if a person indicates that they work part-time, a question should be added in for participants to indicate how many hours they work.

It was also suggested the greyed out boxes in the response section of the question which asks ‘What educational qualifications have you obtained?’ should be made darker to ensure participants understand they are not to fill these sections out.

### **Ethical Considerations**

#### ***Ethical approval***

In April 2011, an application was submitted to NHS National Research Ethics Service Committee North East – Sunderland. Following review in May 2011, the committee gave an unfavourable ethical opinion on the grounds the CF quality of life questionnaire which was an intended addition to the study (Gee, Abbott, Conway, Etherington & Webb, 2000) was ‘not clear / validated.’ To avoid further delay the decision was made to remove the CF quality of life questionnaire from the study and a second application was submitted to the Derbyshire Local Research Ethics Proportionate Review Sub-Committee in June 2011. The study received ethical clearance (Appendix C) following three amendments:

1. The following sentence: ‘If the results show an area where the CF team’s pastoral care could be improved then this can also be addressed’ was removed from the Participant Information Sheet.
2. Circumstances in which confidentiality may be breached were made clear in the Participant Information Sheet.
3. The consent form was removed from the study; completing the questionnaire implied participant consent.

#### ***Informed consent, anonymity and storage of data***

Patients were approached by clinicians within the Leeds regional Adult CF Centre at St James’s Hospital and asked about their interest in taking part in the study. An expression of interest was followed up by an information sheet outlining the aims and purpose of the study. Participants retained the right to not answer questions and withdraw from the study at any time. Any patients who refused to take part were not solicited for recruitment.

All completed questionnaires were anonymised and given a unique identifier number and stored as confidential data in a locked cabinet. The participant identification key which identified participants by cross referencing each unique number, postcode and socioeconomic data were stored in a different locked cabinet at the Leeds regional Adult

CF Centre at St James's Hospital. All electronic files or databases were stored on the authors personal M: drive area of the University of Leeds computer system and the author's personal computer at home, both of which were password protected. The transfer of data was carried out using University email and an encrypted USB.

## SURVEY RESULTS

### Participants

170 patients were invited to take part in the survey; 6 declined and 2 were excluded due to incomplete data. In total, 162 patients, 57% male, mean age 29.3 years (range 17 to 69 years) completed the questionnaire, representing a 97% response rate. 142 (88%) participants were diagnosed with Cystic Fibrosis in infancy ( $\leq 2$  years of age). Mean BMI was 21.9 and mean FEV<sub>1</sub> was 55.6 and 10 (6%) were post-transplant (Table 1).

Table 1 Participant characteristics

N	162
Sex	
Male	93 (57%)
Female	69 (43%)
Age (years)	29.3 $\pm$ 8.7
Diagnosed $\leq 2$ years	142 (88%)
BMI	21.9 $\pm$ 3.4
FEV <sub>1</sub>	55.6 $\pm$ 21.8
Post-Transplant	10 (6%)

*N=162*

### Educational Attainment

93 (59%) participants left school before they were 18 years old. 97 (64%) obtained their highest educational qualifications during school or college; 42 (28%) gained a degree, 9% of which were at Masters or Doctorate level (Table 2).

**Table 2** Highest qualification achieved

Highest qualification achieved	No.	%
None	5	3
GCSE	29	19
BTEC/NVQ	34	23
A Level/AS Level	29	19
HND/Certificate of Higher Education	12	8
Degree	28	19
Masters	12	8
Doctorate	2	1

*N=151*

A logistic regression was undertaken using current age, FEV<sub>1</sub> and socioeconomic status (SES) as predictors of school leaving age of 18 or over (Table 3). No significant predictors were found except for socioeconomic status ( $p < 0.01$ ), although the variance explained was small ( $R^2 = 0.071$ ).

**Table 3** Contribution of variables to the logistic regression for school leaving age of 18 or over

Variables	B	S.E.	Wald	Df	Sig.	Exp(B)
Age	-0.005	0.020	0.075	1	0.784	0.995
FEV <sub>1</sub>	0.003	0.008	0.188	1	0.664	1.003
SES	0.000	0.000	7.285	1	0.007	1.000
Constant	-1.345	0.814	2.730	1	0.098	0.261

A logistic regression was undertaken using current age, sex, FEV<sub>1</sub> and socioeconomic status as predictors of educational attainment at degree level (Table 4). No significant predictors were found except for socioeconomic status ( $p < 0.01$ ), although the variance explained was small ( $R^2 = 0.088$ ).

**Table 4** Contribution of variables to the logistic regressions for educational attainment at degree level

Variables	B	S.E.	Wald	Df	Sig.	Exp(B)
Age	0.002	0.021	0.012	1	0.914	1.002
Sex	-0.229	0.384	0.354	1	0.552	0.796
FEV <sub>1</sub>	-0.006	0.009	0.450	1	0.502	0.994
SES	0.000	0.000	7.850	1	0.005	1.000
Constant	-1.535	1.121	1.875	1	0.171	0.215

Further analysis using t-tests found a significant difference in participants' socioeconomic status between those leaving school at 18 and those leaving school earlier ( $t(154)=2.88, p < .001$ ) and those gaining at least a degree and those not ( $t(149)=2.97, p < .01$ ).

### Employment

At the time of the survey 89 (55%) participants were employed; 29% full-time, 21% part-time, 1% voluntary and 4% studying and working. Classification of occupation is reported in Table 5.

**Table 5** Classification of occupation

Classification of occupation	No.	%
Higher managerial & professional	8	9
Lower managerial & professional	15	17
Intermediate occupations	24	27
Employees in small organisations	14	16
Lower supervisory & Technical occupations	8	9
Semi-routine occupations	12	13
Routine occupations	8	9

$N=89$

Out of the 55% in current employment, 26% were in professional occupations, 27% intermediate, 16% employees in small organisations, 9% lower supervisory and technical occupations, 13% semi-routine occupations and 9% routine occupations.

133 (82%) participants were receiving regular benefits: 126 (79%) received Disability Living Allowance; 21 (13%) Incapacity Benefits; 20 (13%) Housing Benefits; 23 (14%) Income Support; 23 (14%) Council Tax Benefits; and 10 (6%) received Employment and Support Allowance.

A logistic regression was undertaken using age, sex, FEV<sub>1</sub> and highest educational qualification as predictors of employment (Table 6). Current FEV<sub>1</sub> and highest educational qualification were significantly related to being in employment ( $p < 0.01$ ) although the variance explained was quite small ( $R^2 = 0.218$ ). No relationship was found between employment and age and sex of participants.

**Table 6** Contribution of variables to the logistic regressions for employment

Variables	B	S.E.	Wald	Df	Sig.	Exp(B)
Age	0.000	0.021	0.000	1	0.988	1.000
Sex	-0.330	0.375	0.774	1	0.379	0.719
FEV <sub>1</sub>	-0.027	0.009	8.385	1	0.004	0.973
Educational qualification	-0.604	0.160	14.319	1	0.000	0.547
Constant	3.134	1.188	6.958	1	0.008	22.955

### Perceived Impact of CF on Education and Career

Participants' perceptions of the impact of CF on their education and career were bimodally distributed. Participants' mean score for perceived impact of CF on education was 4.24. Twelve (7%) perceived CF to have impacted on their education to a great extent and 29 (18%) reported no impact at all (Figure 1). Participants' mean score for perceived impact of CF on career was 5.45. 30 (19%) perceived CF to have impacted on their career to a great extent and 28 (17%) reported no impact at all (Figure 2).

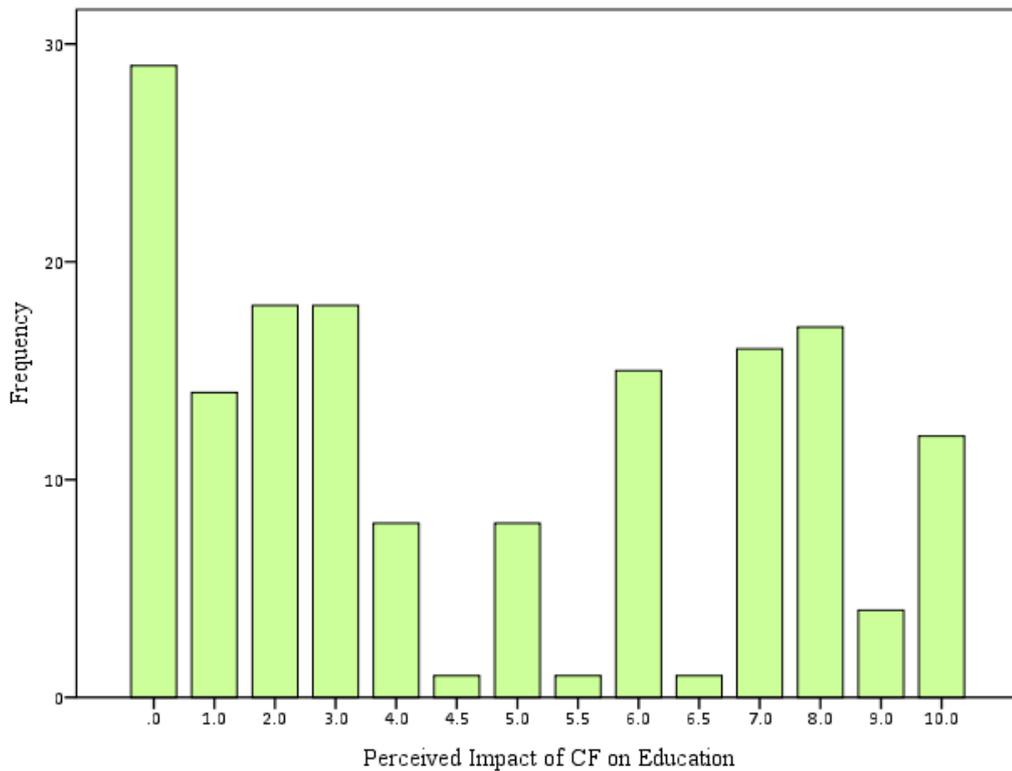


Figure 1 Perceived impact of CF on education

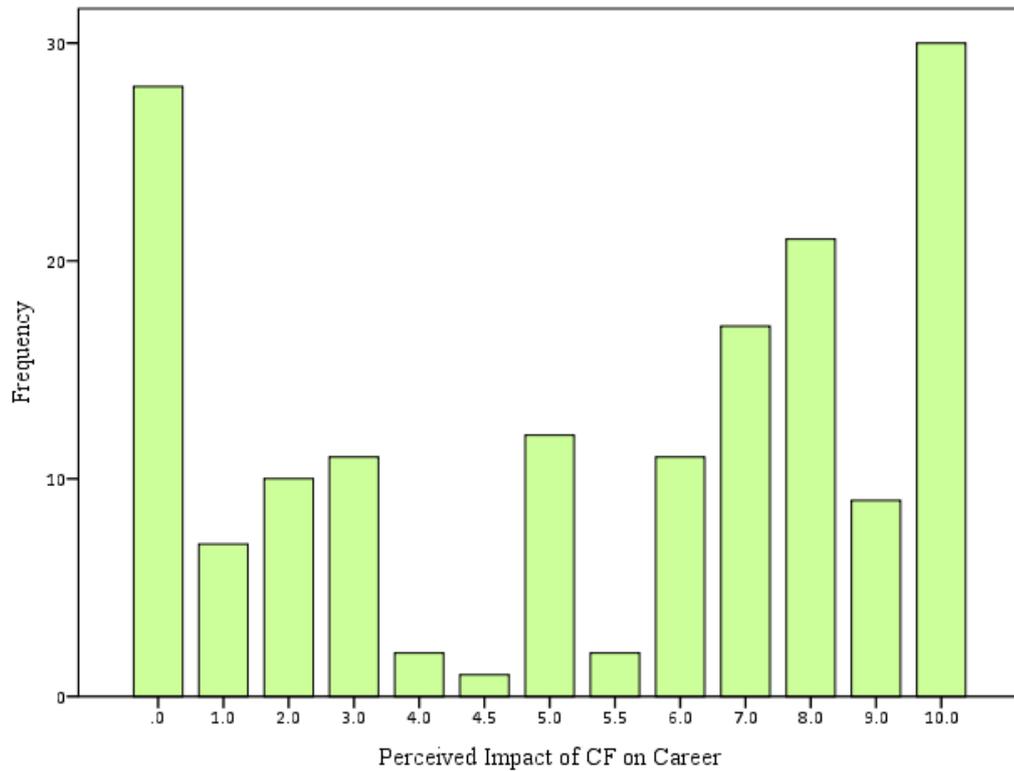


Figure 2 Perceived impact of CF on career

Perceptions of the impact of CF on education were significantly related to perceptions of the impact on employment ( $r = .457$  (159),  $p < 0.01$ ) and both were significantly related to socioeconomic status ( $p < 0.05$ ), but no relationship was found for school leaving age or educational attainment at degree level. There was a significant negative effect for current FEV<sub>1</sub> on perceptions of the impact of CF on career ( $r = -.290$  (159),  $p < 0.01$ ) but not for perceptions of the impact of CF on education ( $r = -.126$  (159),  $p < 0.01$ ).

### Summary of Findings

This survey of the educational qualifications and employment of people with CF included 162 people recruited from a regional Adult CF Centre. Over half of the sample (59%) had left school before they were 18 and only 28% had attained educational qualifications at degree level; somewhat lower than the figure for the UK population, which has been between 35-39% since 2000 (OECD, 2011).

School leaving age of 18 or over and educational attainment at degree level were both strongly associated with socioeconomic status. As is true of the wider population, the lower the participants' socioeconomic status, the more likely they were to leave school at a younger age and the less likely they were to achieve educational qualifications at degree level. The overall numbers are lower in the CF population than in the general population, however.

Neither current FEV<sub>1</sub>, age, sex or highest educational qualification were found to be predictors of school leaving age and neither current FEV<sub>1</sub>, age or sex were predictors of educational attainment at degree level. Participants' current CF disease severity, age, sex and level of education attainment therefore, were not associated with the age at which they left school nor current CF disease severity, age and sex associated with ability to achieve educational qualifications at degree level. It is important to emphasise that the measure of FEV<sub>1</sub> is contemporary and this does not tell us about any relationships with FEV<sub>1</sub> in childhood, though these measures may be correlated.

At the time of survey, 89 (55%) participants were in current employment; 29% fulltime, 21% part-time, 1% voluntary and 4% studying and working. This is somewhat lower than the employment rate for the UK population, which for all 16 to 64 year olds is 70.4% (OECD, 2008). Out of the 55% in current employment, 26% were in professional occupations and 27% in intermediate. The majority (82%) were receiving some level of regular benefits; DLA was the most common received. Current FEV<sub>1</sub> and highest educational qualification were both strongly associated with being in employment. The less severe a participants' CF disease was and the higher a participants educational qualifications were, the more likely they were to be working. Neither age nor sex of participants was found to be predictors of employment.

Participants' perceived impact of CF on their education and career were bimodally distributed. Perceptions of the impact of CF on education were significantly related to perceptions of the impact of CF on employment. Participants therefore, who perceived CF to have impacted on their education to a great extent also perceived CF impacted to a great extent on their career. Perceptions of the impact of CF on education and career were significantly related to socioeconomic status. Participants with lower socioeconomic status therefore perceived a greater impact of CF on their education and

career. However, no association was found for school leaving age or educational attainment at degree level.

Finally, a strong association was found between current FEV<sub>1</sub> and perceptions of the impact of CF on career ( $p < 0.01$ ) but not for perceptions of the impact of CF on education ( $r = -.126$ ). Participants who had more severe CF disease perceived greater impact of CF on their career. As previously discussed the measure of FEV<sub>1</sub> is contemporary and does not tell us about any relationships with FEV<sub>1</sub> in childhood; a possible explanation for this finding.

### **Conclusion**

The educational attainment and employment figures for people with CF are lower than those in the general population. Socioeconomic status was the factor most predictive of school leaving age, educational attainment at degree level and perceived impact of CF on education and career, whereas CF disease severity and level of education attainment (highest qualification) were factors most predictive of employment. Whilst relationships between income and education are widely reported in the general population, a question raised by the current survey is whether people with CF and their families may be disadvantaged in terms of financial security.

It cannot be presumed that medical advances in treatment and improved health mean there are no longer any significant barriers to success. People with CF appear not yet to be achieving the educational and occupational potential of their peers, yet the causes of this are still uncertain. To investigate this in more detail, study two was conceived as a qualitative study of the experiences of education and employment of young people with CF, and their understanding of their experiences.

## CHAPTER III

### **STUDY 2: A QUALITATIVE STUDY OF EDUCATIONAL AND EMPLOYMENT EXPERIENCES**

#### **QUALITATIVE METHODOLOGY**

##### **Design**

This study utilised a qualitative analysis of six interviews with young people with CF discussing their educational and employment experiences and their understanding of the factors that influenced the development and attainment of aspirations. Grounded theory (GT) methodology informed the sampling, data collection and analysis.

##### **Methodological Considerations**

In this section, methodological aspects of the study are considered and the rationale for the chosen methodology discussed.

##### **Quantitative or Qualitative**

Within the field of psychological research quantitative and qualitative methods may be employed to explore a phenomenon of interest. The aim of quantitative methodology is to explain, describe, control or predict a phenomenon of interest via the gathering of numerical data. In contrast, qualitative methodology aims to gain meaning from non-quantified narrative through the gathering of non-numerical data.

Qualitative research attempts to make sense of the world from the participant's view point by unfolding and revealing the meaning of their experiences and lived world (Kvale, 1996). Unlike quantitative methodology which predominantly focuses upon the identification of cause effect relationships, qualitative methodology is concerned with the quality and texture of participants' experiences and the meaning attributed to events (Willig, 2008). Although qualitative methodology can be extremely labour intensive and time consuming, an asset is that the research process does not have to be fixed from the outset; this can provide flexibility for appropriate modifications if difficulties arise (Willig, 2008). A further strength of qualitative methodology is its high ecological validity and its ability to tolerate and theorise contradictions in the data. Unlike quantitative methodology which usually excludes these contradictions as outliers and exclude them from the data, qualitative methodology pays particular attention to these

cases which, it has been argued, enables more thorough understanding of the phenomena being studied (Willig, 2008). Essentially, the primary goal of qualitative research is to describe and explain participants' lived events or experiences with the aim of exploration of meaning or theory generation (Willig, 2008).

There is little qualitative research in the CF literature on education and employment, yet this has the potential to reveal rich data on the experiences, beliefs and aspirations of young people with CF, therefore was the method chosen in the current study.

### **Qualitative Methods**

There are numerous methodological approaches which can be employed in qualitative research. This section will discuss the three most prominent approaches used in psychological research and illustrate the rationale behind the method chosen.

#### ***Discourse Analysis***

Discourse analysis originated in the UK during the 1980s and is today predominantly situated in the field of critical social psychology (Madill & Gough, 2008). The main focus of discourse analysis is language and its function in the construction of phenomena and in particular, the ways in which language portrays meaning and the differences in this across contexts (Willig, 2008). The aim of the researcher is to "focus on the detail of the text, explicating the ways in which phenomena are brought into being through the use of linguistic resources" (Madill & Gough, 2008, pp257). Whilst this method has received praise for exploring the functional nature of language, it has been criticised for providing little insight into the non-linguistic expressions of experience (Madill & Gough, 2008; Willig, 2008).

#### ***Interpretative Phenomenological Analysis***

Interpretative phenomenological analysis (IPA) emerged in the UK during the 1990s. The aim of this method is to capture and explore from the perspective of the participant the quality, texture and meaning of subjective experience (Madill & Gough, 2008; Willig, 2008; Smith, 1996). The role of the researcher in IPA is to gain insight into the participants' views, thoughts, beliefs and experiences of the phenomenon of interest (Willig, 2008). IPA assumes that only through acknowledging the researcher's engagement and interpretation of the data can understanding be achieved. It is therefore acknowledged that the researcher's perspective of the world and their interactions with individual participants may influence analysis. Thus, analysis is seen only as an

interpretation of experience; essentially a co-construction between researcher and participant (Willig, 2008).

### ***Grounded Theory***

Grounded theory (GT) was developed in the 1960s by two sociologists, Glaser and Strauss, following dissatisfaction with the ability of quantitative methods used in sociology to capture participants' lived experiences (Madill, Jordan & Shirley, 2000). Glaser and Strauss defined GT as an exploratory inductive method which aims to facilitate the process of discovery through identifying and integrating categories of meaning from data to develop a theory grounded in the participants' experiences (Willig, 2008; Glaser & Strauss, 2009). With the principal aim being the systematic generation of theory, the end-product of GT should be an explanatory framework with which to explain and understand the phenomenon of interest. GT enables researchers to make sense of what is going on in the field setting and is today among the most influential and widely used models for carrying out qualitative research (Charmaz, 2006; Glaser & Strauss, 2009).

The focus of the current study is to explore the educational and employment experiences of young people with CF. Though experience is mediated by language, the focus of the study is not language and its function is the construction of experience, therefore discourse analysis was not the method chosen. Although IPA and GT methodology both aim to gain insight into participants' experiences of a phenomenon of interest, IPA focuses upon the in-depth essence or nature of individual experience, whereas GT focuses upon the development of a theoretical model to explain the social context, cause or consequence of shared experience (Willig, 2008). It was hoped that GT would allow the author to capture the rich educational and employment experiences of young people with CF and build a theoretical explanation of why educational and occupational potential is not achieved. With this in mind, GT was the method chosen.

### **Epistemology**

There are a number of epistemological stances a researcher can take when carrying out qualitative research. This will vary depending on how the researcher conceptualises their role in the process of producing knowledge, the type of knowledge they aim to produce and the assumptions they have about the world (Willig, 2008). Indicating the epistemological position from which the researcher approaches their method is extremely important, as each position inevitably affects their understanding of

the data and leads to differing implications for the evaluation of the research (Marshall, 1986; Willig, 2008).

Over the years GT has been applied and interpreted in many ways sparking many debates and controversies within the field. Even the founders, Glaser and Strauss parted company following a dispute over how GT should be practised. Whilst Glaser stood by his original version of GT which, influenced by positivist epistemology, discouraged the imposition of the researchers own meanings onto the data, Strauss began to criticise this method for under playing the role of the researcher (Willig, 2008). Subsequently, a more prescriptive GT emerged advocating step-by-step guides and coding paradigms. This introduced a new deductive element to the once exclusively inductive method, which Glaser argued imposed a rigid framework upon the once flexible method, undermining the original purpose of GT (Willig, 2008).

Many more versions and adaptations of GT have since appeared. Most recently, there has been the development of a social constructionist version of GT. This approach proposes that the interactions between the researcher and the data are predominantly the cause of any emergence of theory (Charmaz, 2006). It therefore acknowledges that the research process and ultimately the research findings can be shaped by the methodological, theoretical, philosophical and personal orientation of the researcher. The researcher recognises that the theory produced is not the only truth about the data; it is just one particular reading (Willig, 2008).

To summarise, Glaser's positivist position of GT emphasises the role of the researcher as nothing more than a witness and neither their expectations nor assumptions influence the data. The data is assumed to speak for itself with little attention paid to the role of the researcher (Willig, 2008). The constructionist position however, recognises the researcher as an active agent in the research process. This stance acknowledges the inherent subjectivity in the construction of knowledge and accepts the inevitability that the researcher's personal and cultural viewpoints might influence the research process. To provide a better understanding of the subjective experiences of participants and best answer the aims of the study, a constructionist version of GT was adopted.

### **Methods of Data Collection**

There are many different methods of data collection which qualitative researchers can employ. Depending on the goal of the research and the type of data considered, qualitative data collection and analysis can vary greatly (Madill & Gough, 2008). This section will discuss three dominant approaches within qualitative research and indicate the rationale behind the method chosen.

Due to fears around the risk of cross-infection in people with CF, it is recommended that those with CF should not come into close contact with one another (Cystic Fibrosis Trust, 2004b). Therefore, the focus group, although a valuable method for collecting data, was not chosen.

The structured interview however, was considered. This approach consists predominantly of closed questions in which participants mainly respond to a number of predetermined categories (Smith, 1995). Using this approach the researcher is able to elicit from participants the precise information they need (Smith, 1995). Whilst this method has been praised for its reliability as a measure, the interview is constrained to the framework created by the researcher, leaving little room for exploration or discovery (Smith, 1995). As little is known about the educational and employment experiences of people with CF, it was important that the study provided participants with the opportunity and flexibility to explore their experiences. There was a risk the structured interview may inhibit this path of discovery, therefore this was not chosen.

One method which overcomes some of this difficulty is the semi-structured interview. Using this approach the researcher develops an interview schedule comprised of open questions and prompts aimed to elicit the information they want. Not only does this approach facilitate a strong element of discovery, its structured focus permits the researcher to steer the interview to obtain the kind of data that will answer their research aims (Willig, 2008; Gillham, 2005). The ability of the researcher to discuss topics which emerge in the interview gives a fuller picture of the phenomena of interest (Smith, 1995). Although the development of the interview schedule and subsequent transcription of accounts can be time consuming, the semi-structured interview enables the researcher to maintain the focus of interest whilst providing participants with the opportunity to discover and discuss their insights. To elicit the richest information to best answer the research aims of the study, the semi-structured interview was the method chosen.

## **Ethical Considerations**

### ***Ethical approval***

In April 2011, an application was submitted to NHS National Research Ethics Service Committee North East – Sunderland, following review in May 2011 the study received full ethical clearance (Appendix D).

### ***Informed consent***

To take part in the study it was important all participants gave informed consent. Suitable participants were identified by clinicians within the Leeds regional Adult CF Centre at St James's Hospital and asked about their interest in the study. An expression

of interest was followed up by an information sheet outlining the aims and purpose of the study (Appendix E) and verbal consent for their details to be passed onto the author.

From here, the author made contact with the participant and arranged an appointment to meet and discuss the study further. At this appointment, participants were provided with the information sheet again and provided the opportunity to ask questions. If in agreement, participants completed a written consent form (Appendix F). Participants retained the right to stop the interview, choose not to answer questions and withdraw from the study at any time.

Any patients who refused to take part or were unable to provide informed consent were not solicited for recruitment.

### ***Anonymity***

The author explained to participants the usual clinical guidance regarding confidentiality at the start of the interview i.e. confidentiality could be breached if any information they gave suggested they or another person might be at risk; this wasn't necessary for any participant.

All information corresponding to the participant such as digital audio recordings and interview transcripts were anonymised and given a unique identifier number. At the end of interviews all participants were asked if there was anything they had discussed they didn't want reporting; no participant requested this.

The transcription of the interviews was carried out by a third party transcriber who was familiar with transcribing confidential information. Any identifying features within transcripts were removed and quotes for the final report were sensitively selected to ensure participants remain anonymous.

### ***Other ethical considerations***

For some participants talking about experiences of education and employment and considerations for the future was upsetting. The author was mindful of this and where necessary asked participants if they wanted to stop the interview and enquired about whether they would like to talk to a psychologist attached to the centre; only one participant expressed a preference for doing this. Contact details of the psychologists were outlined in the patient information sheet.

### ***Storage of data***

Participants' signed consent forms were stored as confidential data in a locked cabinet at the author's home. All electronic files were stored on the authors personal M: drive area of the University of Leeds computer system and the author's personal

computer at home, both of which were password protected. The transfer of data was carried out using University email and an encrypted USB.

On completion of the study all documentation and electronic files will be returned to the Doctorate of Clinical Psychology office. All documentation will be stored in a locked filing cabinet within the department and all electronic files will be stored on the N: drive for a period of three years.

### **Sampling**

A ‘purposeful sampling’ method was initially used to recruit participants. In the study, clinicians within the Leeds regional Adult CF Centre at St James’s Hospital were asked to refer potential participants to the author. Clinicians were asked to refer patients between the ages of 18 and 24 years with a diagnosis of CF from birth and who were not in higher education or stable employment. The rationale for the selection of the sample were that participants were young enough to have experienced the medical advances in treatment, yet were seemingly not achieving the potential benefits longevity should now provide i.e. were not in current education or employment.

Half way through the recruitment phase a ‘theoretical sampling’ method was employed. This enabled the author to identify gaps in the data and seek data to refine and elaborate categories in the emerging theory (Charmaz, 2006). Based on data from the first three participants, the author asked clinicians to refer potential participants who were not in education or employment, yet had had previous experience of educational and occupational achievement. With this in mind, participant four was theoretically sampled. She had obtained various educational qualifications and had worked in a number of different professional settings, yet at time of interview was neither in education nor employment. After recruitment of participant five who was also female, participant six, a male, was theoretically sampled using the same criteria.

### ***Participants***

Six participants, 3 male, 3 female, were interviewed. Ages ranged between 21 and 24 years and all had a diagnosis of CF from birth. All participants attended the Leeds regional Adult CF Centre and none were in higher education or stable employment. Individuals diagnosed with CF late in life were excluded from the study. Participant characteristics are outlined in full in Chapter IV.

## **Recruitment**

### ***Participants***

Suitable participants were approached to ask about their interest in the study by clinicians within the Leeds regional Adult CF Centre. An expression of interest was followed up by an information sheet outlining the aims and purpose of the study and verbal consent for their details to be passed on to the author. From here, the author made contact with the participant and arranged an appointment to meet and discuss the study further. At this appointment, participants were provided with the information sheet again and provided the opportunity to ask questions. If in agreement, participants were asked to complete a written consent form before starting the interview.

## **Data Collection**

### ***Development of the interview schedule***

A semi-structured interview schedule comprised of 19 open-ended and non-directive questions was designed to capture participants' subjective experiences of education and employment, and their understanding of the factors that influenced the development and attainment of aspirations.

Initially, questions 1 to 4 aimed to explore participants' early experiences, hopes and aspirations, questions 5 to 10 their experiences of education, and questions 11 to 15 their experiences of employment. The final section, questions 16 to 19, aimed to explore participants' reflections on experience, their thoughts on the present and for the future. Central to each of these sections were questions examining the role and influence of CF.

### **Pilot interview**

A pilot interview was conducted in September 2011 with a non-CF adult known to the author. No modifications or amendments were made following this.

### **Interview one amendments**

After conducting interview one in October 2011, the author was aware there had been little exploration of the participants' individual experiences of CF and the interview on the whole was more structured than originally anticipated. To facilitate a more conversational and focussed narrative, three conversational style questions were added to the opening section of the interview: One question asking participants' reasons for taking part in the study and two questions aimed at exploring participants' understandings and individual experiences of living with CF. The interview schedule,

now comprised of 21 questions, was used for the remaining five interviews (Appendix G).

Interviews were carried out by the author between October 2011 and January 2012. Interviews were conducted at participants' homes, except participant six, who was interviewed within a private room at the Leeds regional Adult CF Centre at St. James's' Hospital. Interviews lasted between 25 and 75 minutes and were recorded using a digital voice recorder.

### **Data Analysis**

All interview audio recordings were uploaded onto a password protected computer and transcribed by a third party. Once transcribed, the author listened to the interviews again to check transcriptions matched the spoken interview and to help familiarise with the meaning of the text. Between February and May 2012, transcripts were analysed using GT. An example excerpt from a transcript is presented in Appendix H.

### **Coding**

Each transcript was analysed using a system of coding. Coding is the process in which the researcher selects, separates and makes sense of the data; moving from concrete statements in the data to analytic interpretations (Charmaz, 2006). Charmaz (2006) defined coding as shaping the analytic frame from which a researcher builds their analysis.

Transcripts were analysed in three stages using a system of open, axial and theoretical coding (Strauss & Corbin 1990; Charmaz, 2006). Throughout the analysis process two other important features of GT were simultaneously employed; constant comparison and memo-writing. The next section discusses each level of coding in detail with illustration of worked examples, followed by explanations of constant comparison and memo-writing. Firstly, the overall process of GT analysis is depicted in Figure 3.

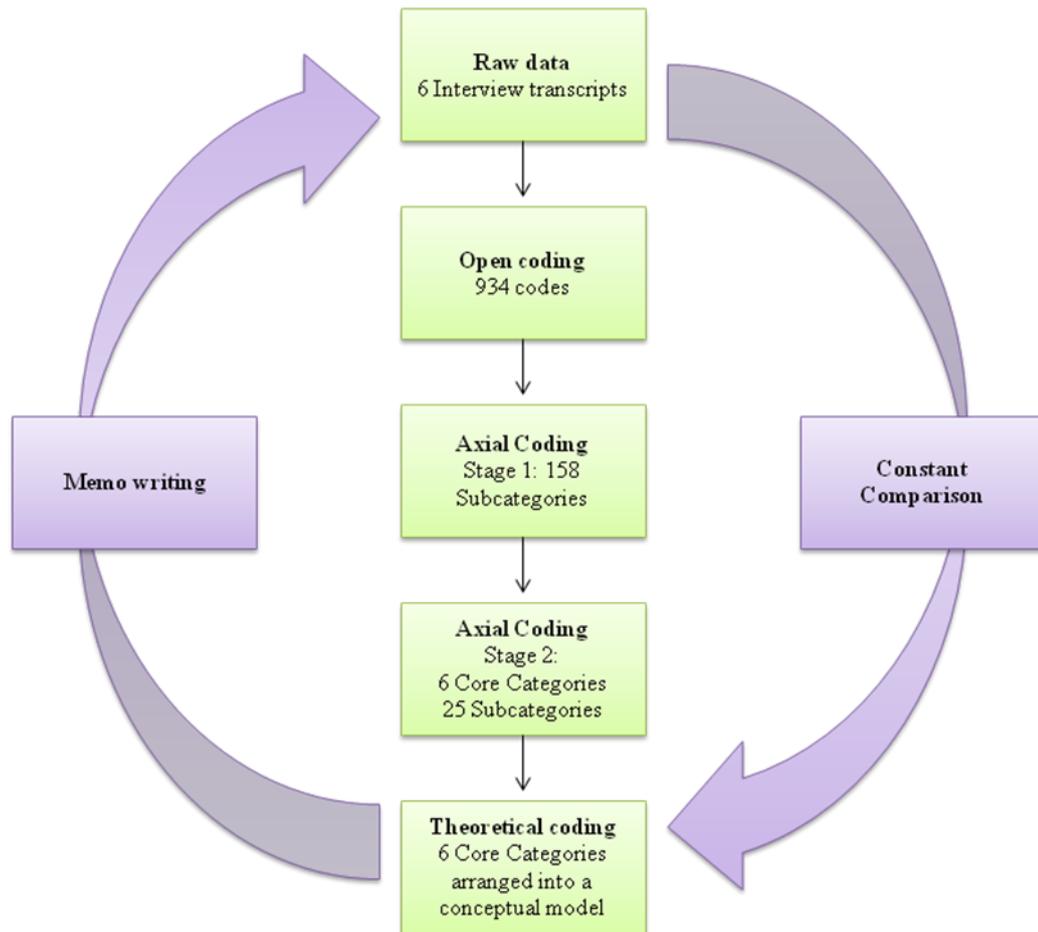


Figure 3 Process of GT analysis

### ***Open coding***

The first level of analysis is open coding, this is where the researcher starts to define and make sense of what is happening in the data. This is used as an initial tool for opening up the data and helps provide the researcher with analytic directions with which to further data collection and analysis (Charmaz, 2006).

The author began this process by taking one transcript at a time, reading the data closely and labelling each line of the written text with individual units of meaning or code (Glaser, 1978). As the author read each line she asked: “What does this mean?” and “How can this be defined?” (Charmaz, 2006, pp. 51). It was important throughout this process for the author to stay close to the data and remain open to different theoretical directions (Charmaz, 2006). The author checked and compared data within and across transcripts to ensure the open coding captured the meaning of the data and removed or re-categorised those that didn’t (constant comparison). The first level of analytic interpretation produced 934 codes. An example of open coding taken from an excerpt from transcript one is shown in Table 7.

Table 7 Example of open coding from transcript one

Participant quote	Example of open coding
<i>I didn't want to, I didn't like school, I didn't have a good experience at high school. I got bullied a lot and I missed a lot of school and and I left in year 10. So I didn't stay full term at school anyway 'cos I was bullied a lot and I was behind on work and teachers didn't seem to understand.</i>	Didn't like school Experience of being bullied Absence from school Left school early; Bullied Fell behind on work; Teachers didn't understand
<i>Like if I, I'd sit there with my hand up in class saying I don't understand the work 'cos I'd be so far behind and they'd say well you should do your work in hospital and I said but I do but you don't send the same work. So I used to struggle a lot and they didn't understand and a lot of them just, I don't know they just seemed right off with me because I wasn't there all the time. They just weren't that understanding about my CF wasn't the school.</i>	Asking for help Falling behind on work Teacher expectations Difficulty getting work Struggling in school; Lack of understanding School response to absence Lack of understanding

### ***Axial coding***

The second stage of analytic interpretation is axial coding. This is where the data, now fractured into open coding, starts to be brought back together into a coherent whole (Strauss & Corbin, 1990). This takes place in two stages.

The first stage of axial coding is where the researcher reviews the open codes both within and across transcripts (constant comparison) and looks for similarities in meaning between them. Codes which are similar are grouped together into subcategories, forming an initial analytic framework. During this stage, the author organised the 934 open codes into 158 subcategories.

The second stage of axial coding helps clarify and extend the analytic strength of emerging ideas by encouraging the researcher to be more selective and conceptual (Glaser, 1978; Charmaz, 2006). Here, the researcher looks for conceptual links between the individual subcategories by asking 'How are these related?' During this stage, the author organised the 158 subcategories into 25 subcategories and six core categories. Using the open coding illustrated in Table 7, Table 8 demonstrates an example of open to axial coding.

***Theoretical coding***

The third and final stage of the analysis is theoretical coding. Here the goal of the researcher is to look for relationships between the subcategories and core categories with the aim of developing a conceptual model which explains the subject of research. This is the highest level of coding whereby the theory is formed (Charmaz, 2006). Glaser (1978) defined this stage as the fractured story being woven back together again.

During this stage, the author reviewed the 25 subcategories and 6 core categories and looked for a coherent, theoretical structure which best explained participants' experience. To help organise her thinking, the author used individual pieces of paper to represent each core category and subcategory and mapped out relationships diagrammatically. Once a conceptual model of best fit was found, the author returned to the transcripts and checked the theoretical structure represented participant accounts (constant comparison).

Table 8 Example of open and axial coding from transcript one

Open code	Subcategory	Core Category
Didn't want to stay on at school	Motivation to persevere: to carry on or leave and not return	Processes: CF as a Mediator of the Lived Experience
Didn't like school	Motivation to persevere: to carry on or leave and not return	Processes: CF as a Mediator of the Lived Experience
Bullied	Experience of prejudice and discrimination	Processes: CF as a Mediator of the Lived Experience
Absence from school	Missing education	Processes: CF as a Mediator of the Lived Experience
Left school early	Educational experience and achievement	Accounts of the Lived Experience
Bullied	Experience of prejudice and discrimination	Processes: CF as a Mediator of the Lived Experience
Fell behind on work	Missing education	Processes: CF as a Mediator of the Lived Experience
Teachers didn't understand	Level of Cystic Fibrosis understanding in others	Processes: CF as a Mediator of the Lived Experience
Asking for help	Provision of educational support and help	Processes: CF as a Mediator of the Lived Experience
Falling behind on work	Missing education	Processes: CF as a Mediator of the Lived Experience
Teacher expectation	Missing education	Processes: CF as a Mediator of the Lived Experience

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Difficulty getting work	Missing education	Processes: CF as a Mediator of the Lived Experience
Struggling in school	Missing education	Processes: CF as a Mediator of the Lived Experience
Lack of understanding	Level of Cystic Fibrosis understanding in others	Processes: CF as a Mediator of the Lived Experience
School response to absence	Level of Cystic Fibrosis understanding in others	Processes: CF as a Mediator of the Lived Experience
Lack of understanding	Level of Cystic Fibrosis understanding in others	Processes: CF as a Mediator of the Lived Experience

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## **Other Procedures in GT Methodology**

Throughout all three stages of GT analysis the author engaged in two simultaneous processes: constant comparison and memo-writing.

### ***Constant comparison***

As reported, GT methodology builds analysis from the ground up via three distinct stages of coding with the aim of developing a theoretical model which explains the subject of research. To ensure this process takes shape, constant comparison, a core component of GT is employed. This requires the researcher to constantly move back and forth through the data, comparing actions, experiences and interpretations; the aim of which is to confirm or discount emergence of developing theory (Charmaz, 2006).

During open coding, where the data was initially fragmented, the author used the constant comparative method to look for similarities and differences in open coding both within and across transcripts. This involved checking novel codes in later transcripts with those that had appeared in previous transcripts and where necessary removing or re-categorising codes which were repetitious or ambiguous.

At both stages of axial coding, constant comparison was again a crucial tool. As the author began to organise open codes into subcategories and core categories, codes grouped together were checked and compared to make sure they represented the same concepts.

In the final stage of analysis, where the theoretical model was created, the final comparison was made. Here, the author returned to transcripts and checked the conceptual model was a true representation of participants' experiences.

### ***Memo-writing***

Memo-writing is another core component of GT. This involves the researcher noting down any thoughts or ideas they have during the analysis e.g. any signs of emerging theory or anything that seems confusing. By doing this, the researcher is able to record what is happening in the data and keep a record of the analytic process (Charmaz, 2006).

Memo-notes were used by the author as crucial memory aids and prompts throughout the analysis process. She noted down thoughts, ideas, interesting or confusing data or any emergence of theory. Not only did these help illustrate directions to pursue and gaps in the data that needed filling they often served as useful guide for constant comparison. Figure 4 provides an example of a memo-note made by the author.

*Participant 6: "It's difficult because I'm from a really professional family we're a kind of middle class sort of high achieving family and those aspirations are there but I'm honest with myself about it if you know what I mean, I kind of, I don't, it's difficult, I won't, I'd love to be successful but I don't expect it." (Page 7; 144-147)*

Aspirations are present, but expectations of achievement appear lowered? Similar reported by participant 1 (page 45: 949-951)

Figure 4 An example of a memo-note

## Quality Control

### ***Researcher reflexivity***

One of the main criticisms of qualitative methodology is the space they afford the subjectivity of the researcher (Madill, Jordan & Shirley, 2008). Adopting a constructionist version of GT the author recognised that her perspective and position (both as a person and theorist) may have shaped and influenced the research process. To try and manage some of the difficulty posed by this, the author throughout the research process reflected on her role as researcher; recognising how her age, sex, ethnicity, personal experience of the subject and personal reactions to the research context and data, might have influenced data collection and analysis. The author describes her position below, so that the reader can interpret and understand the research and consider any claims in relation to these.

### Situating the author

I am a 28 year old white, British, female from the north-west of England. I have experienced acute illness in my personal life and as a psychologist in clinical training have worked in a clinical setting with people with acute and chronic illness. Prior to the study I had never met anyone with CF.

Having experienced both in my personal and professional life the many challenges and difficulties young people with chronic illness can face, the subject of research is of great interest and importance to me and something I feel extremely passionate about.

To date, there is little qualitative research in the CF literature exploring the subject of research. Whilst the paucity of CF research inspired me to explore this topic further, novel insights presented in the disability literature were used to guide and focus my research.

Across both my educational and professional training I have had experience of using various research methods. Prior to starting my clinical training I worked as a research assistant on a number of large-scale quantitative studies and throughout both my undergraduate and doctorate training I have had experience of conducting small scale qualitative research. Prior to the current study, I had never used grounded theory.

In planning the current study, I became close with members of the CF community, meeting patients and professionals within the Adult CF Centre at St James's Hospital. Meeting professionals, I heard anecdotal accounts of how young people with CF weren't achieving the benefits longevity should now provide and how the cause of this was still uncertain. Hearing these accounts motivated me further in my quest to uncover and reveal the reasons and understandings underlying this.

Conducting study one in the Leeds regional Adult CF centre I was able to meet and talk with patients in an outpatient setting and gain some insight into the nature of CF and the demands of its treatment regimen. I did not meet any of the participants from study two during the recruitment of study one, yet all had completed the survey at time of interview.

Across data collection and analysis of study two I experienced a number of personal reactions to the research. Listening to participants' accounts, I experienced feelings of shock and sadness and on many occasions, admiration and awe. I feel honoured to have been allowed to open the door into the intimate worlds of these participants and afforded the opportunity to hear their accounts of their lived experience. I am extremely passionate about research which incorporates the service-user perspective and feel a responsibility to ensure the voices of these participants are heard.

### ***Supervision***

To check the credibility of the analysis, over the course of the study the author engaged in regular supervision. This enabled her at each stage of the analysis to discuss the development and organisation of the data. She discussed the emerging theory and presented themes in relation to data extracts, which helped to refine and define categories. This was particularly helpful during theoretical coding as it was often a useful forum for exploring the development of the model (theoretical formulation). The author also attended a peer

supervision group for qualitative researchers during analysis and a smaller group for those using GT.

*Non-psychological perspective*

For coherence and understanding, on completion of analysis, a non- psychology graduate who did not have CF was asked to read the written results. No changes were made following this.

## CHAPTER IV

**QUALITATIVE RESULTS**

This chapter discusses the findings from the six qualitative interviews with young people with CF. A description of the overall sample is presented first, followed by discussion of individual participants and the author's reflections from the interview. The six core categories representing the data are then presented followed by the description of the theoretical formulation. Each core category is then described in detail, with discussion of subcategories and supportive illustrative quotations.

**Description of the Sample**

Six participants, all of whom had an early diagnosis of CF ( $\leq 2$  years of age) were interviewed by the author between October 2011 and January 2012. Participants' ages ranged from 21 to 24 years and half of the sample was male. At time of interview, half of participants reported living independently from their family. A range of educational and employment experiences were reported. All described experience of school and college, though varied in terms of educational achievement and age they left. All but one participant reported experience of employment and at time of interview no participant was in education or employment. An overview of demographic and social characteristics is presented in Table 9.

Table 9 Participant demographic and social characteristics

N	Sex	Age	Independent living	Age left education	Experience working
1	F	23	Yes	18 years	No
2	M	24	No	16 years	Yes
3	M	21	Yes	18 years	Yes
4	F	22	No	22 years	Yes
5	F	24	Yes	17 years	Yes
6	M	23	No	23 years	Yes

At time of interview, two participants were on the referral list for transplant. Further clinical characteristics for each participant in the year prior to interview are described in Table 10.

**Table 10:** Participant clinical characteristics in year prior to interview

N	FEV <sub>1</sub> % range	Course of IV antibiotics	Inpatient days	Nasogastric feeding	Requires oxygen	Diabetes	Transplant referral list
1	16-33%	5	51	Yes	No	Yes	No
2	14-26%	6	50	No	Yes	No	Yes
3	71-89%	1	0	No	No	Yes	No
4	26-44%	6	22	Yes	No	No	No
5	16-26%	10	23	No	Yes	Yes	Yes
6	24-36%	2	38	No	No	No	No

### ***Participant one***

Participant one is a 23 year old female who lives with friends. She left school aged 15 with no formal qualifications after she failed to sit her GCSEs because of CF. After leaving school she joined a college and completed her Level one NVQ in Childcare. She started her Level two the following year but due to deterioration in health was unable to finish. She left college aged 18 and has not returned to education since. At time of interview, she had never been employed. She described her experience of trying to get a job in a hairdressing salon, but reported this had been unsuccessful because of CF.

Participant one appeared comfortable talking about her experiences though this was concisely and succinctly spoken. The interview seemed to be much more structured than I had hoped. There was little conversational flow and as a consequence I found myself relying on the schedule of questions to keep the interview going. I wondered how much this was a consequence of being the first interview and all the anxieties that came along with this, and how much this was the consequence of a succinct narrative. Overall the interview lasted 25 minutes, much shorter than anticipated.

***Participant two***

Participant two is a 24 year old male who lives at home with his mother and stepfather. He left school aged 15 with few formal qualifications to work in the family's carpentry business. Over the next few years, he worked on and off in this job. Aged 22 he gave up work following deterioration in his health and was placed on the referral list for transplant. During this time, he spoke of attending college, but this was short-lived.

The interview with participant two lasted 46 minutes; again the narrative was concise and succinct. I found myself wondering whether this was going to be a continued characteristic of the participants I sampled. As I listened to his experiences, I found myself feeling both shocked and saddened. There was a sense that CF had prevented him from achieving his goals. Reflecting on these feelings after the interview, I realised I hadn't truly acknowledged or understood the severity of CF or its effects until that point.

***Participant three***

Participant three is a 21 year old male who lives with his partner of three years. He left school aged 14 with no formal qualifications after he failed to sit his GCSEs because of CF. After leaving school he received home tuition for a year but only in the subject of art. Over the next two years, between the ages of 16 to 18, he attended three different colleges where he studied art, employment skills and IT. He left each course early, without qualifications, because of reasons associated with CF. He left education aged 18 and has not returned since. He reported his only experience of employment as just under a week's work in a hardware store.

Interview three lasted 75 minutes and was the longest of all the interviews. Unlike the previous two interviews, this felt much more conversational in style. Although I felt more skilled in conducting the interview, he also had lots of experiences with which he seemed keen to share. It was apparent discussing these experiences aroused feelings of upset and anger in him. Something which appeared novel in his narrative was fears that being in education and employment would lead to deteriorations in health. This was something I hadn't heard in previous interviews. This left me questioning whether fears surrounding the future were potentially limiting engagement in education and employment. Again, the role of CF and its apparent impact on life was a stark reality.

***Participant four***

Participant four is a 22 year old female who lives at home with her mother and siblings. At school she obtained GCSEs and age 16 she left to go to college where she started studying Psychology, Chemistry, Biology and General Studies AS levels; she left after only passing one. Aged 17 she decided she wanted to work as a welder and soon after leaving college, was offered a position. After six months working as a welder, she decided she wanted to return to college where she completed her NVQ in engineering. From here, she gained employment as an engineering apprentice for five months. Aged 18 she left and gained a position as a Personal Assistant in an IT company where she worked for the next two years until she was made redundant at aged 20.

Over the last year, she has volunteered for the Red Cross and Yorkshire Ambulance Service as a community first responder and has returned to college and undertaken an Access course in Health Science. She plans to apply to university later this year and in the interim hopes to gain employment in a care home.

Participant four was interviewed for 52 minutes. At first, she appeared shy to talk, but as the interview progressed seemed more at ease. There were times throughout the interview that she appeared to well up with emotion, although she seemed reluctant to express this. Unlike the previous participants interviewed she was still working towards the achievement of her life goals. I found myself feeling in awe of her achievements as against so much adversity she had continued to achieve. I wondered what was different in this participant from the others I had interviewed; what had made this individual continue to study and work towards her desired career when others hadn't. Something that appeared influential was her outlook on CF and the future.

***Participant five***

Participant five is a 24 year old female who lived at home with her partner of eight years. At school she attained ten GCSEs and went on to college to attain AS levels in the subjects of Sociology, Biology, English Language and Literature. Throughout college she had worked in a supermarket and a hairdresser. Age 17 she left college and gained fulltime employment working in a call centre for a catalogue company. After 3 years she was asked to leave this position because of her high sickness absence. At time of interview she was on the referral list for transplant and hoped post-transplant she would be able to return to education and in the future gain employment.

Participant five was interviewed for 41 minutes and again this felt very conversational in style. Within her accounts appeared two parallel narratives. Like previous participants, there was a narrative which focused on how CF had stopped her from achieving an education and employment. A second narrative which existed however was one whereby she acknowledged she had not helped her situation by not looking after herself properly and adhering to her medication regime in adolescence. Whilst most teenagers go through a rebellious stage, I found myself wondering whether people with CF aren't able to recover from this rebellious period. Once they don't adhere to their medication and become unwell or they don't get any qualifications, it seems it is very difficult to try and recover. As she spoke of her experiences and the challenges and consequences she had faced, she appeared strong and pragmatic and focussed on a hopeful future after transplant. I felt struck by her apparent resilience and like that of the previous interview, found myself in awe of her achievements.

#### ***Participant six***

Participant six is a 23 year old male. He lives at home with both his parents and is in a relationship. He obtained GCSEs and went on to college to study Biology, Chemistry, English Literature and Language at AS level. After two attempts to complete this due to repeated CF illness and admissions to hospital, he left aged 18, without attaining his qualifications. He returned to college aged 20 to study music though left in his second year. Aged 23 he attended college again to study software design although he left again due to an admission to hospital. He reported experiences of working in a supermarket and a retail store; the longest period of employment was reported as four months.

Participant six engaged well with the interview, talking confidently and openly about his experiences. The interview process flowed smoothly with little prompting or direction needed and drew to an end after 70 minutes. A unique narrative within this interview was a description of how his experiences of being unwell and the uncertainty which surrounded his life expectancy had changed his perspective on life. This left me questioning again, whether fears around the future may be acting as a barrier to education and employment.

### Theoretical Formulation

Using a Grounded Theory coding method 934 open codes were produced and organised into 158 axial codes. These were reduced into 6 core categories and 25 subcategories and organised into a theoretical structure (Table 11).

Table 11 Theoretical structure of core categories and subcategories

<b>Core Category</b>	<b>No.</b>
<b>Core Category 1: Living with Cystic Fibrosis</b>	<b>6</b>
1.1 Being the patient	6
1.2 Adolescence: Treatment adherence and control	3
1.3 Cystic Fibrosis taking control of life	4
1.4 Mastering Cystic Fibrosis	5
<b>Core Category 2: Hopes for the Life to be Lived</b>	<b>6</b>
2.1 Educational aspirations	5
2.2 Occupational aspirations	6
2.3 Hopes for the future	5
<b>Core Category 3: Shaping and Limiting Aspirations</b>	<b>6</b>
3.1 What I want	6
3.2 Family influences	4
3.3 My Cystic Fibrosis	6
<b>Core Category 4: Accounts of the Lived Experience</b>	<b>6</b>
4.1 Educational experience and achievement	6
4.2 Occupational experience and achievement	5
4.3 Educational and occupational hopes for the future	6



### **Description of the Theoretical Formulation**

The first core category describes participants' accounts of what it is like to live with CF and provided a context for the discussions that followed. The next two core categories focussed on participants' recollections of the hopes and aspirations that they had for their education, career and life in general. It consists of a category in which participants' hopes, dating back to childhood are described, followed by a category consisting of the influences that shaped, and in some cases limited hopes and aspirations.

The next two core categories describe the actual experiences participants had of education and employment. Core category four is a brief, descriptive summary of the experiences reported by participants and discussion of their future hopes for education and employment in adulthood. Core category five is a longer and more detailed account of the many ways in which CF intruded on their experiences, grouped into environmental factors, the role of influential others, and the self. The final core category contains participants' reflections on the life they have lived so far, how CF has influenced this, and on how reality compares with the aspirations of youth. Figure five depicts an overall model of the theoretical formulation.

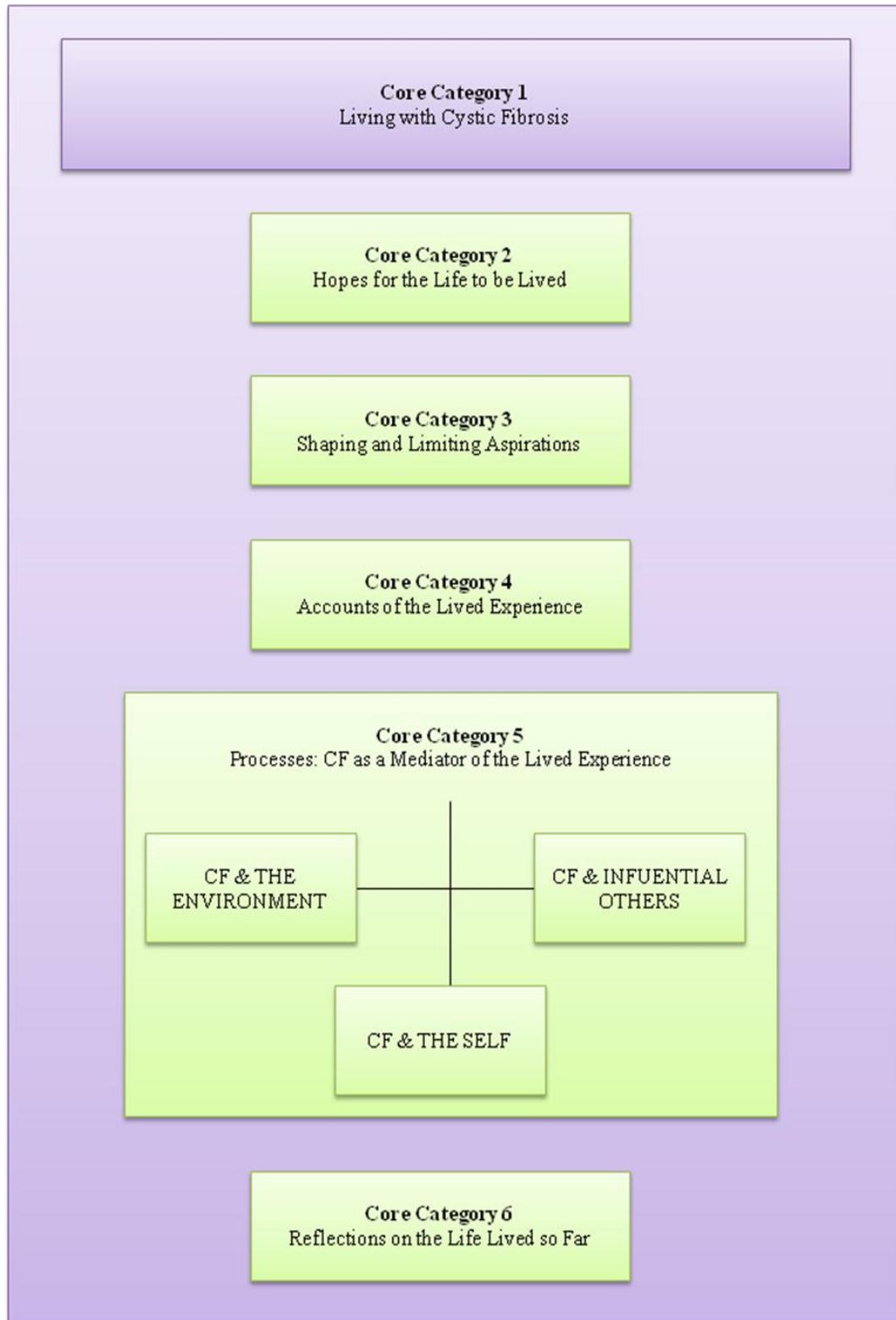


Figure 5 Overall model of theoretical formulation

## Core Categories

The next section will describe the six core categories in detail, with discussion of subcategories and supportive illustrative quotations. The number of participants contributing to each will also be reported.

### Core Category 1: Living with Cystic Fibrosis

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This core category describes participants' accounts of living with Cystic Fibrosis and was contributed to by all six participants. It contained four subcategories: Being the patient; Adolescence: treatment adherence and control; Cystic Fibrosis taking control of life; and Mastering Cystic Fibrosis.

#### 1.1 Being the patient: 'I feel poorly every day'

All participants reported experience of being 'poorly' and 'in and out of hospital' because of CF:

*"I feel poorly every day" ... " it's not like it's very different if I'm really poorly It's just a little bit worse than the day before ...." (Participant 4)*

Participants reported gaining an understanding in childhood that something was 'up' with them due to recurrent episodes spent in hospital, however, most (4/6) recalled at this time, having little understanding and awareness of CF:

*"I just went into the hospitals all the time and basically going to the hospital every other week or not every other week, every month and yea, you seem to think something's up with you." (Participant 2)*

*"I don't think I was aware that I had CF really when I was little, I knew I was poorly but I didn't know it was CF." (Participant 1).*

Knowledge, understanding and awareness of CF were reported by the majority of participants (5/6) to have increased with age:

*“You do understand and you do learn about your illness ... I guess you become conscious really don’t you when you’re about 13 ....” (Participant 6)*

*“Probably, probably around 12, 13” ... “I got the full understanding of what all my medications do and if I don’t take them these are the consequences.” (Participant 5)*

The majority of participants (4/6) reflected on what it is like to live with CF; describing this as ‘weird’, ‘rubbish’, ‘hard’, ‘difficult’, ‘annoying’ and a ‘pain’. Two participants specifically described CF as a ‘rollercoaster’; one in particular, spoke of how he felt they had spent their life ‘sat on the sidelines’. Living with CF however was reported by one participant as having its ‘fun times’, he recalled how visiting different hospitals he had been able to travel the UK:

*“But it has its’ fun times and all ... You get to go to hospitals and I know that doesn’t sound right good, but you get to go to other hospitals and round everywhere else, round the country and that ....” (Participant 1)*

One participant reported when you’re feeling well, you’re really good, though recalled how it can also be annoying and frustrating:

*“When you’re feeling really well you’re really good, happy, can be a bit annoying, I describe it more that frus, well it can be slightly frustrating ....” (Participant 5)*

Finally, several (3/6) participants commented on the hidden nature of CF, stating many people often do not notice they are unwell:

*“But I know a lot of people what don’t know what CF is until I tell them and then they’re like woah, and then they say god I didn’t think you were that poorly ‘cos you don’t look poorly so.” (Participant 1)*

## **1.2 Adolescence: Treatment adherence and control: ‘I decided to rebel and not do my treatment and so since then, things have gone downhill quite a lot’**

Several participants (2/6) recalled that during their early childhood they had little responsibility and control over their treatment and as a consequence their adherence to treatment and subsequent health was good:

*“Obviously when I was a child I was well medicated and looked after because it was not really in my control.” (Participant 6)*

During adolescence however, participants reported their management of CF ‘turned to chaos’ when they began to take more responsibility and control over their treatment. Half of the participants (3/6) described how they started to ‘neglect’ their health and ‘rebel’ against doing their treatment. They recalled they were ‘desperate to be normal’ and in ‘denial’ of CF and its consequences. Poor adherence to treatment however, was reported to catch up with them and participants spoke of their health deteriorating and frequency of treatment and admissions to hospital increasing as consequence:

*“I seemed to just rebel against the world and think, I’m sort of invisible mode where, oh it happens to other people, it won’t happen to me so, yeah I just sort of thought well if I don’t take them for a few weeks what difference is that going to make? And I’d take my treatment for like a week, and then not take it for another 3 or 4, maybe a month and I thought ahh, I’ll wing it, I’ll be fine. And then it catches up with you in the end.” (Participant 5)*

*“I think it was denial if you know what I mean so I just sort of I wasn’t doing my nebulisers and it’s such a cliché but I was just, I think I was just desperate to be normal even though I’m not if you know what I mean so and I think that’s really where it went down the pan a bit.” (Participant 6)*

*“I decided to rebel and not do my treatment and so since then, things have gone downhill quite a lot, hence I’m on the transplant list, and my treatment now is roughly 3 out of every four weeks I’m on treatment.” (Participant 5)*

### 1.3 Cystic Fibrosis taking control of life: ‘You just don’t get to do as much stuff as what everybody else does’

Several participants (4/6) reported that living with CF restricts and constrains aspects of their life. One participant described how ‘there’s a lot of stuff you’ve got to avoid and stuff that’s really impractical health wise to do’, whilst others discussed being unable to do the things they want, such as leave their home, play sports, go on holiday or start a family:

*“Just because you can’t just go and do it ... just go on holiday but you can’t when you’ve got CF cos you’ve got to have a flight test and if you fail you can’t go and you can’t just go and have a baby because that affects your CF ... Everything evolves round your CF really.” (Participant 1)*

Several participants (3/6) reported feeling like they weren’t in control of their CF. One participant described how she can become unwell with little warning, which is particularly problematic when in employment:

*“I can’t guarantee when I’m gonna be off and I can’t phone up and say oh I’m not going to be in next week ‘cos I’m going to be poorly you never know when you’re going to be poorly with CF.” (Participant 1)*

One participant recalled how their inability to control CF prevents him from being able to make plans and commitments:

*“Just I think it just comes from like not really I mean because you’re only in control a certain amount, like you can kind of exercise and do all your drugs and your physio and stuff which I do but it’s kind of, even then it’s not a kind of it’s not a dead cert that you’re going to be alright if you know what I mean” ... “So that’s where the anxiety comes from, not, and not being able to plan things and make commitments and stuff like that.” (Participant 6)*

#### 1.4 Mastering Cystic Fibrosis: ‘You just become used to it ... it becomes everyday life’

The majority of participants (5/6) described CF as a ‘part of life’ with which they have become used to:

*“Not really I’ve become used to it, sort of like other things when you’re slowly getting, your chest’s getting worse sort of adjust to the new routine of things and erm yeah you just, you just become used to it ... it becomes everyday life.” (Participant 5)*

The realisation of the need to look after themselves and adhere to treatment, and the positive effects of doing this were reported by most participants (4/6) to have increased with age. Participants described doing exercise and taking their treatment to keep themselves fit and healthy and reported feeling better for doing this:

*“I just seemed to have pick up a bit in myself and I was doing more exercise and I just felt like in, my prime then” ... “I was going to the gym and keeping myself fit and healthy and everything ....” (Participant 2)*

One participant reported realising that doing her treatment ‘really does help’ and another reported how looking after himself ‘makes it all worthwhile when you can do what you want’:

*“Exercise is like going to work and then it affords me certain things like the health to go and see a band that I really like and stuff like that” ... “Yeah well it’s the way I see it and, it kind of certainly last year I went to see a band at [PLACE NAME] and it just seemed to make it all worthwhile really ‘cos I mean just like you know walking in winter and blowing a gale, and hailstones on the beach and you know it’s freezing and yeah it just makes it all, all worthwhile ....” (Participant 6)*

## **Core Category 2: Hopes for the Life to be Lived**

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Core category two describes participants' hopes for life, dating back to childhood and was contributed to by all six participants. It contained three subcategories: Educational aspirations; Occupational aspirations; and Hopes for the future.

### **2.1 Educational aspirations: 'I wanted to go to college'**

The majority of participants (5/6) recalled in early childhood and adolescence they had hopes of going to school and college and achieving educational qualifications:

*"You know, go to school, possibly college, possibly Uni ...."*

*(Participant 5)*

*"I wanted to go to college." (Participant 4)*

*"I wanted to do like it in a qualification" ... "I wanted to get my NVQs."*

*(Participant 4)*

### **2.2 Occupational aspirations: 'I wanted to be a nurse'**

Over half of the participants (4/6) recalled as children, what jobs they wanted to do when they grew up:

*"I wanted to be a nurse." (Participant 1)*

*"I wanted to be a vet." (Participant 4)*

A small number of participants (2/6) however, described how they didn't think about the future and what they wanted to be as children:

*"Didn't have any" ... "as a child I certainly don't remember thinking I want to be an astronaut or anything stupid like that." (Participant 6)*

It was only as adolescents that they recalled thinking about what they wanted to do:

*“Certainly not as a child, when I was younger, say a young teenager I wanted to go into medicine.” (Participant 6)*

Across the course of the interviews, participants spoke of how they have wanted to do ‘loads of different things’ with their futures. Participants spoke of wanting to be a ‘Midwife’ ‘Engineer’ ‘Game designer’ and ‘Paramedic’. One participant recalled wanting to work with his father in the family business, whilst several (2/6) had hoped they would join the Army.

### **2.3 Hopes for the future: ‘I wanted a farm and that, I don’t know really I just that I wanted like to be with somebody’**

The majority of participants (5/6) reported various other hopes for their futures. Participants recalled as children, having hopes to ‘travel’ ‘move abroad’ and ‘play football all day’. One participant in particular, spoke of how she thought as a child she would be like everybody else; namely, meet someone and get married; whilst another recalled how she hoped she would move to the countryside. Several participants (2/6) also discussed hopes for health and wellbeing. In particular, one participant, as an adult, spoke of his hopes to live to 40 years and older:

*“I just thought I would be like everybody else I suppose” ... “Meet someone, get married ....” (Participant 5)*

*“I wanted a little cottage” ... “In the countryside” ... “And that I wanted a farm and that, I don’t know really I just that I wanted like to be with somebody.” (Participant 4)*

*“Just to be well, and not be in and out of hospital all the time ....” (Participant 1)*

*“I’d preferably like to hit 40 onwards ....” (Participant 3)*

### Core Category 3: Shaping and Limiting Aspirations

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The third core category describes the variety of influences reported by participants to have shaped and limited their hopes for life. This was contributed to by all participants and contained three subcategories: What I want; Family influences; and My Cystic Fibrosis.

#### **3.1 What I want: ‘I just love kids I absolutely adore kids so I just wanted to work there’**

All participants described how their hopes and aspirations for life had been shaped by their personal interests, predominantly what they ‘liked’ and ‘enjoyed’. Several participants (2/6) reported how they wanted to work with children because they ‘love’ and ‘adored’ kids. Similarly, one participant recalled as a child, he wanted to be in the army because of their interest in weapons and warfare and another spoke of wanting to work in computer game design because he thought it ‘looked fun’. Some participants (2/6) specifically recalled how in adolescence a need and desire to earn money had been influential, whilst another recalled she wanted to be a paramedic because it was a ‘practical’ and ‘caring and rewarding’ job:

*“I just love kids I absolutely adore kids so I just wanted to work there.”*  
(Participant 1)

*“I wanted to do it I thought it would be a good thing to do, looked fun.”*  
(Participant 3)

*“I was learning to drive. I needed a car and the parents wanted rent.”*  
(Participant 5)

### 3.2 Family Influences: ‘Doctor down to son, goes into medicine’

The majority of participants (4/6) spoke of how different familial influences had shaped their hopes for life. One participant described how he had wanted to go into the army because both his grandfathers had been soldiers, whilst another recalled it ‘seemed logical’ to follow in his father’s footsteps as a doctor. One participant also spoke of how encouragement from her parents to achieve and work hard had been influential:

*“Encouragement from my parents mainly” ... “They’ve, my dad’s always worked, my mum stayed at home when we were little to look after us both but then as soon as she was able she got a job, so we’ve always had that instilled in us that you know, to get your money, you go out you earn it ....”*  
(Participant 5)

### 3.3 My Cystic Fibrosis: ‘Obviously it was because of my CF because I was with doctors all the time’

All participants reported Cystic Fibrosis had influenced their hopes for life. Several participants (2/6) recalled how exposure to the hospital environment in early childhood had been influential in shaping what they wanted to be when they grew up. They reported how they had wanted to be a doctor and a nurse because they had spent much of their early years surrounded by these professionals. One participant in particular, spoke of how she wanted to look after something else as being in the hospital environment she had been used to people looking after her:

*“Obviously it was because of my CF because I was with doctors all the time” ... “Because I have got CF, I like thought I knew quite a lot about what doctors do. Obviously I was a bit like naive when I was little so I thought oh it’s just CF that people have got, so I just thought oh well I know everything anyway so I could be a doctor, so that’s why I wanted to be a doctor.”*  
(Participant 4)

*“Maybe like just looking after something else” ... “Yeah, like making it better because obviously like with going to the hospital and things, like I’ve been used to people looking after me and so I’m like want to look after other things ....”* (Participant 4)

A minority of participants (2/6) however, recalled little influence of CF on the development of hopes in early childhood. One participant stated CF had been such a small part of his life during his early years; it had not been influential in shaping his hopes to be a doctor:

*“Well yeah like I say, medicine probably because of my dad and when I was a child, I don’t yeah I don’t think CF has anything to do with it at all” ...*

*“Because it was, it was such a small part of my life” ... “it just wasn’t even an issue at all.” (Participant 6)*

Interestingly, half of the participants reported as they have grown older and more aware of their CF, they have noticed more of an influence of CF on their hopes for life. Several participants (2/6) reported a growing awareness of their reduced life expectancy and how this had ‘restricted’ their aspirations. Although both reported the continued presence of hopes and aspirations, fears about the future had led to doubt and lowered expectation that these would be achievable:

*“It [CF] affected me thinking whether I’d be able to do it but not if I wanted to do it, I knew that I definitely want to do it.” (Participant 4)*

One participant talked of how he was scared to think about the future because of the uncertain and progressive nature of CF:

*“That’s the way I see it, I don’t, I don’t ever think, I don’t think about the future because it scares me shitless, I feel like you know, it’s like staring down the barrel of a gun. You know, I don’t, I just don’t think about it at all.” (Participant 6)*

*“The uncertainty of it and because it’s a progressive illness, it, do you know what I mean, it’s only going to get worse so I just don’t really think about it ....” (Participant 6)*

He reported how because of these fears he had little expectation of achievement:

*“Apart from enough to think, it’s only going to get worse so I’m not going to think about it as stupid as that is but yeah so I don’t really have any expectations.” (Participant 6)*

Further discussion of these findings will take place in Core Category five, subcategory 5.8, subsection 5.8.2.6.

#### **Core Category 4: Accounts of the Lived Experience**

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Core category four provides descriptive accounts of participants’ lived experience and was contributed to by all six participants. It contained three subcategories: Educational experience and achievement; Occupational experience and achievement; and Educational and Occupational hopes for the future.

##### **4.1 Educational experience and achievement**

All participants reported experience of attending school and college, though this varied in terms of their educational achievement. Only half of the participants obtained GCSEs. These participants (3/6) went onto college to study AS Levels in the subjects of Psychology, Chemistry, Biology, Sociology, English Language and Literature. Only two participants however, completed these in full, neither of who went onto study at A Level. Other subjects studied by participants at college were Childcare, Art and Design, ICT, Music, Software Design, Engineering and Health Science. All participants discussed experience of leaving education early; only half of the participants reported achieving their desired college qualifications, the remaining participants (3/6) left college without this. At time of interview, none of the participants were in education.

##### **4.2 Occupational experience and achievement**

All but one participant reported experience of having worked. Participants’ employment histories ranged from brief episodes of working in a Supermarket, Hairdressers and a Retail and Hardware Store, to more long-term positions as a Telesales Operator, Engineer Apprentice, Personal Assistant and an employee within the family’s carpentry business. Several participants (2/6) also reported experience of voluntary work. One

participant spoke of having worked as a community first responder for an Ambulance Service and another, an assistant in a nursery. All participants reported experience of leaving employment early. At time of interview, none of the participants were in employment.

### **4.3 Educational and occupational hopes for the future**

Over half of the participants (4/6) reported hopes to return to education or employment in the future. One participant reported hoping to return to college and re-sit her GCSEs:

*“I want to go to college and resit, well do my GCSEs ‘cos I didn’t do em and then just take it from there ....” (Participant 1)*

Two participants spoke of how they hoped they would gain employment post-transplant. One participant stated that she hoped post-transplant the world would be her ‘oyster’ and she could get to where she wanted to be:

*“I’m still, I’m still optimistic that post transplant I may get there.”  
(Participant 5)*

At the time of interview only one participant was actively planning to return to education; she spoke of applying to University later in the year and in the interim hoped to gain employment in a care home. The remaining two participants however, reported no intentions to return to education or employment.

## Core Category 5: Processes: CF as a Mediator of the Lived Experience

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The fifth core category describes the many ways CF has influenced and shaped participants' lived experiences and was contributed to by all participants. Overall, it contained eight subcategories grouped into environmental factors, the role of influential others, and the self. Grouped into environmental factors were subcategories: Missing education; Missing opportunities to achieve; Missing employment; and Not meeting requirements. Grouped into the role of influential others were subcategories: Provision of educational support and help; Level of CF understanding in others; and Experience of prejudice and discrimination. Grouped into CF and the self was the final subcategory: Motivation to persevere: to carry on or leave and not return.

### CF & THE ENVIRONMENT

#### 5.1 Missing education: 'I was away from school a lot'

All participants reported experience of missing education because of CF. Participants gave examples throughout their lives of having repeated periods of absence due to being unwell and admitted to hospital for IV antibiotic treatment:

*"I was away from school a lot with being in hospital and on my IVs and just with bugs ...." (Participant 4)*

Several participants (2/6) specifically recalled how their deliberate non adherence to treatment in adolescence led to deterioration in health, resulting in increased need for treatment and more time absent from education (Core Category one, subcategory 1.2):

*"Around 16 when I stopped doing all my stuff, and then obviously the treatment increased which meant more time off school, more time off college ...." (Participant 5)*

Several participants (2/6) reported CF had had little effect on their education in early childhood. One participant in particular, recalled how she was 'no different to anybody else' in these early years, however as they grew older and treatment increased all recalled

how CF intruded. Repeated absences from education were reported by all participants as resulting in them falling behind in class and having to try and catch up when they returned:

*“I was going in the hospital and like nearly every 2 months for 2 weeks so I’d do all my work and get all like caught up, go in hospital for 2 weeks, miss 2 weeks of work and then come back and then try and catch up again.”*  
(Participant 2)

Being absent from education and trying to catch up was reported by participants as becoming more problematic as they grew older and educational difficulty increased. Several participants (3/6) specifically recalled how they often had difficulty getting the necessary work they needed. One participant spoke of how in primary school his family were easily able to organise and coordinate the work he needed, but in secondary school this proved more difficult as the number and complexity of subjects he studied and the number of teachers with whom he needed to coordinate increased:

*“When I was at little school ... my sister would go get my homework or work and bring it me through to the hospital ... I was doing good with my work then, and then as soon as I went up to high school ... when it’s one classroom it’s not that bad ‘cos you can go get your work ... but at high school they split you up... there’s classroom there isn’t there, then you’ve got to walk and then there’s another classroom and then another block for a different” ... “and about 16 different books and then doing that once a day, it was hard work and then eventually that stopped ‘cos they just well, it just stopped really.”*  
(Participant 2)

Exacerbating this difficulty further were reports from some participants (2/6) that the educational expectations of their school and hospital differed. One participant specifically described how it was expected by school that she carry on her work in hospital; though this was difficult as school often did not send the same work:

*“I’d sit there with my hand up in class saying I don’t understand the work ‘cos I’d be so far behind and they’d say well you should do your work in hospital and I said but I do but you don’t send the same work.” (Participant 1)*

Another however, recalled how in hospital there was little expectation that he did his school work. Although he was encouraged to try and do his school work, he reported how he could often do what he wanted:

*“Cos I was in the hospital and school at [HOSPITAL NAME] ... she’d try and make you do school work but if you didn’t want to do it she didn’t like make you ... you just get it into your head then that oh well I’ll do this today instead of my work ....” (Participant 2)*

Several participants (2/6) spoke of how they ‘used to struggle a lot’ in school because of the difficulties described. One participant in particular, recalled how she used to get fed up:

*“I missed a lot of school so and I used to get fed up ‘cos I used to miss a lot of stuff at school ....” (Participant 1)*

Another spoke of how repeated absences from college resulted in him losing his footing socially:

*“Just kind of you know dipping in and out and catch up, losing your footing socially” ... “Yeah because obviously you know things progress when you’re not there and then you come back and it’s sort of the same but it’s not really the same ....” (Participant 6)*

He recalled how he often felt awkward walking back into college after being absent:

*“When you disappear for half a term like me for college and you can’t, it’s awkward walking back ....” (Participant 6)*

### **5.2 Missing opportunities to achieve: ‘I never even had the chance to do GCSEs’**

Half of the participants (3/6) also reported specific examples of how CF impacted on their opportunities to achieve educational qualifications. Some participants (2/6) recalled they were unable to sit their GCSEs because of CF, whilst another remembered that being on treatment during these exams had caused her difficulty:

*“Yeah so you know I never even had the chance to do GCSEs at all.” (Participant 3)*

*“I was due on my treatment around my exam time” ... “So it’s like caused a problem with the exams ‘cos I was obviously tired.” (Participant 5)*

### **5.3 Missing employment: ‘I was struggling to do fulltime’**

Half of the participants (3/6) also reported missing work because of their CF:

*“My treatment was a lot more regular, it was every 3 sort of 2 or 3 months by then and I had the big surgery as well so I had a lot of time off ....” (Participant 5)*

One participant spoke of how she was struggling to work fulltime and reduced her working hours to try and help with this, but soon fell ill again and ended up back in hospital:

*“I was struggling to do full time, so I dropped down to 15 hours a week and I was over 3 days. So I managed that for a while and then again got pneumonia and ended up in hospital for 6 weeks ....” (Participant 5)*

Another reported that she missed an interview because of an admission to hospital:

*“I didn’t go to them interviews ‘cos I was in hospital so like that’s like ... I was really poorly like over Christmas and at the start of the year when it was my interviews for them two and I just wasn’t fit enough, I couldn’t have gone ....” (Participant 4)*

#### **5.4 Not meeting requirements: ‘It limits you really because of the practicalities’**

All participants’ reported difficulty meeting requirements. Participants specifically reported difficulty meeting the requirements of education and employment because of their CF. One participant reported that he was unable to join the army because of his CF, stating he wasn’t physically ‘fit enough’. Whilst another believed that to have a job she needed to be ‘reliable’ and ‘good at timekeeping’; skills which were hard when living with the unpredictable nature of CF (Core Category one, subcategory 1.3):

*“It’s hard ‘cos the the employer wants somebody what is reliable and what can be there and obviously we can’t get somebody to go in and speak to them and say well they can’t be here twenty four - seven.” (Participant 1)*

*“Having time off all the time and stuff you’d think well they’re not reliable, they’re not good at timekeeping and that when you’ve got a job, you’ve got to be good at all them things but with CF you can’t really be reliable and be up to timekeeping because obviously we never know when we’re going to be poorly ....” (Participant 1)*

Furthermore, the majority of participants (5/6) reported that a lack of educational qualifications prevented them from pursuing the careers they wanted:

*“Not that you have to be any less clever to be a paramedic but my qualifications what I’ve got like limit me to applying to being a doctor ....” (Participant4)*

In contrast, participants reported difficulty meeting the requirements of CF when in education and employment. The majority of participants (4/6) described how they experienced difficulty maintaining their treatment regime when in education and employment. One participant spoke of how he couldn't do his treatment and go to college. He recalled how he often had to make a choice, miss his medication or miss college:

*"You've got loads of medication to do before you go and you end up actually either missing your collage or you're missing your meds like so it's kind of the thing where you choose what do I do so." (Participant 3)*

He spoke of how he often fluctuated between the two:

*"I just mixed and matched, I just was like, I can't miss my tablets all the time and stuff so maybe you know once a week I'd probably miss college instead you know, maybe more." (Participant 3)*

One participant reported it became harder to manage the amount of work in college and maintain her treatment regimen as educational difficulty increased:

*"Yeah they start, the treatment became a bit more regular sort of every 4 months ... and it began to get a little bit harder to manage the amount of work, you know what college is like, the amount of work you've got to actually do with all the fit all the treatment in ...." (Participant 5)*

Several participants (2/6) also reported a number of requirements and practicalities of CF which needed to be taken into account when considering education or employment. Namely, is there a CF centre nearby? Will they be able to sustain their study or work? What hours will they be working? And what allowance will they have for leave? One participant reported his employability was limited by these practicalities as it was unlikely any one company would be able to support all his requirements:

*“Because it [CF] limits you really because of the practicalities” ... “I can’t really think of a big company that could support all of my requirements that I’d want to work for.” (Participant 6)*

## CF & INFLUENTIAL OTHERS

### **5.5 Provision of educational support and help: ‘They just wanted to stick you in a room with all the other misbehaving kids’**

Provision of educational support and help was discussed by the majority of participants (4/6). Half of the participants (3/6) reported receiving some form of support and help in education. Several (2/6) spoke of receiving one to one sessions with teachers in school, whereas one participant reported having a special team assigned to help her catch up in school. It was this participant who despite experiencing difficulties in her early years at college, managed to complete an NVQ in engineering, an access course in Health Science and was the only participant planning to apply to University later this year (Core Category four, subcategories 4.1 and 4.3). Another participant also reported that she had special conditions for exams in college because of CF. All participants (3/6) reported these provisions as beneficial:

*“Whenever I missed school due to being ill, they always sent work home so I’d always have stuff to do and they always said if you can’t get it done don’t worry, we’ll catch you up when you get back and so I’d get back and I’d have a little one on one session about what I’d missed ....” (Participant 5)*

*“Although like at school it was a lot easier to catch up because obviously they were quite supportive ‘cos they have like, a special like team that” ... “Yeah that like look after people who do miss a lot of school and because of like medical conditions or things like that like disabilities ....” (Participant 4)*

Not all provisions put in place by school were reported by participants as beneficial, however. Several participants (2/6) reported how perhaps to try and help them catch up or perhaps because it was the only place available, they were put in a class with ‘misbehaving’ peers. One participant specifically recalled how this hindered rather than helped his learning:

*“They just wanted to stick you in a room with all the other misbehaving kids and it’s how can you learn with that. You can’t.” (Participant 2)*

Another participant recalled when provided with home tuition ‘there was no chance of getting anything out of it’ when he realised he was not being taught the full curriculum. He asserted his school did little to help rectify this:

*“When he got here it was just you know, yea I’m here to teach art it’s like, now else? And he’s like, I don’t do owt else so. But they just weren’t having any of it when you tried to tell them about it what they’d hired and stuff so it was a case of just you know, may as well do some art instead of nothing.” (Participant 3)*

An absence of support and help in education was reported by the majority of participants (4/6); half (2/4) reported this absent from school and several (3/4) college. One participant attributed her poor educational achievement in college to the lack of support and help she had received:

*“School was interested in the bright people and didn’t care if you was, well if you needed a bit of help they were they weren’t, It weren’t there really.” (Participant 2)*

*“In college because there was no real support, like there was no support from the tutors because it was different tutors all the time so no one got to know you and there was no support like if I missed a lesson like even if I asked for the work to be kept, you know like to be given to me next lesson, there was always an issue” ... “That’s like why I did so bad in my lessons because there wasn’t that support like to give me my work and for me like to help me catch up ....”*  
(Participant 4)

### **5.6 Level of Cystic Fibrosis understanding in others: ‘They just weren’t that understanding about my CF’**

Another issue which was reported by the majority of participants (4/6) was level of CF understanding in others. Several participants (2/6) recalled how their teachers and tutors had understood about CF and the difficulties they encountered in education:

*“People are generally quite, teachers and stuff are quite understanding ....”*  
(Participant 6)

However, some (2/6) described professionals in school and college had lacked this understanding:

*“They didn’t understand and a lot of them just, I don’t know they just seemed right off with me because I wasn’t there all the time. They just weren’t that understanding about my CF wasn’t the school.”* (Participant 1)

One participant spoke of how the education system doesn’t acknowledge ‘a physical disability’ which is ‘more hidden’. He described how people in the education system are ignorant and not willing to learn:

*“Just plain ignorance and lacking like, I don’t know what the word is but not willing to even learn you know, you try and explain all this to them and it’s just like it goes over the top of the head and they’ll like just stare at you blankly and be like, aw, well just don’t next time or whatever and it’s like you just have not listened to a word I’ve said so it’s just complete ignorance.”*  
(Participant 3)

Participants also reported a lack of CF knowledge and understanding outside of the education system, stating many people, especially employers, don't know or understand about CF:

*“Because I think some people are just ignorant towards CF ... I don't think a lot of people understand what CF is.” (Participant 1)*

### **5.7 Experience of prejudice and discrimination: ‘Once I'd told them about my CF and stuff they weren't interested’**

Several participants (2/6) also reported experience of CF-related prejudice and discrimination in education and employment. Both participants described experience of being ‘bullied’ by peers in school because of CF:

*“Yea they all used to call me a pill popper or druggie or a dwarf ‘cos I was small obviously that's ‘cos of my CF or I used to get called stuff about being skinny and and obviously that's my CF.” (Participant 1)*

One participant also spoke of how he felt they had been ‘victimised’ by their tutors in college:

*“It was just felt like complete victimisation from the entire course” ...  
“basically throughout the entire year, everything seemed to be my fault ....”  
(Participant 3)*

He recalled a particular incident where a tutor had asked him to leave the classroom for complaining about being unwell and reported how this had caused him some upset:

*“I turned up about 10 minutes late one time and I was like you know, sorry I'm late erm I've not been good I've been coughing up blood and stuff all morning and he just went like get out of my class I don't want to hear you complaining about it and stuff” ... “Something like that being said to you, you just end up really upset.” (Participant 3)*

Another participant also recalled how she was refused a job in a hairdressing salon because of CF:

*“I tried to get a job in a hairdressers but then once I’d told them about my CF and stuff they weren’t interested” ... “She said to me erm what’s Cystic Fibrosis so I started to explain that it was my breathing an my chest but also my stomach and she said oh it wouldn’t be ideal, I said why, she said working in a hairdressers. I said but why’s that, she said it will affect your chest and we don’t want you coughing all over the customers.” (Participant 1)*

She recalled how this incident had left her feeling angry and uncomfortable:

*“So I was right mad then and I said but it shouldn’t be like that and then we started arguing so I just left ‘cos I was just made to feel right uncomfortable.” (Participant 1)*

## CF & THE SELF

### **5.8 Motivation to persevere: to carry on or leave and not return**

#### **5.8.1 The self: ‘I wasn’t really committed to the course’**

The majority of participants (5/6) recalled how a decision to leave education had been influenced by them as individuals. One participant specifically recalled she left college due to a lack of commitment and enjoyment:

*“I just, because I wasn’t really committed to the course, because I just felt like oh I don’t really want to be here because I wasn’t enjoying it.” (Participant 4)*

Other reasons discussed by participants were being ‘unhappy’ and feeling like they ‘weren’t learning anything’. One participant in particular, described how he left college because the course he had enrolled on didn’t turn out to be what he had expected, he recalled how ‘it was slave labour’.

Another reported she left college because she was ‘fed up’ and wanted to see how she ‘coped’ with employment:

*“I’m getting a bit fed up really so I thought well, year out, I can always come back and finish off the A levels” ... ”So I just decided that it was time to get a job and see how, see how I coped with proper work ....” (Participant 5)*

### **5.8.2 My Cystic Fibrosis: ‘I just kept getting, well not poorly but the CF then made me stop’**

All participants recalled how CF had been influential in their motivation to persevere with education and employment. Whereas several (2/6) participants reported CF had motivated them to keep trying, all reported how CF had influenced their motivation to leave education and employment and in some cases not return.

#### 5.8.2.1 CF as motivation to carry on: ‘I just wanted to do well for myself you know, prove that you know CF doesn’t always have to hold you back’

Several (2/6) participants reported CF had motivated them to persevere with education and employment. One participant described how she wanted to stay on in education as a child because she wanted to do well for herself and prove CF didn’t have to hold her back:

*“I just wanted to do well for myself you know, prove that you know CF doesn’t always have to hold you back and I could, if my friends could do it, why couldn’t I?” (Participant 5)*

Another recalled how after a long period of CF-related illness he decided to get a job because he was bored and wanted some structure and routine in his life:

*“I did that because I was bored and I wanted some routine and structure to my life and it served that purpose.” (Participant 6)*

He spoke of how having a job boosted his self esteem:

*“And it certainly boosted my esteem just to have a job even though it was bad.” (Participant 6)*

#### 5.8.2.2 Treatment adherence and deteriorations in health: ‘I just kept getting, well not poorly but the CF then made me stop’

All participants reported how difficulties with adherence to treatment and deteriorations in health had led them to leave education and employment. Half of the participants (3/6) reported difficulties maintaining their treatment regimes had led them to leave education and employment. One participant specifically described how she left her job as a welder because the dirty work environment affected her health and long hours had prevented adherence to treatment:

*“Yeah just ‘cos with my welding as well like obviously it’s in a dirty environment like engineering so it affected my chest a bit and ‘cos it was long hours I couldn’t do my treatment and so that was like, it was why I totally gave up being an engineer, why I didn’t go back into it and but I still do enjoy it ....” (Participant 4)*

Deteriorations in health often resulting in admissions to hospital were also reported as influencing participants’ motivation to leave. Most participants (4/6) reported that this had been a reason they left education and several (2/6) employment:

*“I had to leave half way through my level 2 because I wasn’t well at all ....” (Participant 1)*

*“I just kept getting, well not poorly but the CF then made me stop.” (Participant 2)*

Several participants (2/6) recalled they left employment following medical advice from their doctors:

*“My doctors and that were all advising me to stop because dust, you know off the sawdust and that was getting off my chest. (Participant 2)*

Leaving employment was not always reported to be the participants’ decision, however. One participant spoke of how due to a high absence rate she was asked to leave work:

*“I was more or less asked to leave before I was sacked due to illness.”  
(Participant 5)*

She spoke of being annoyed at this decision but recalled there was nothing she could do as she needed to continue with her treatment:

*“I was a little bit annoyed, yeah definitely annoyed but not much I could have done ‘cos I need to continue having treatment. It’s not as if I can just go oh well, bugger treatment, you know ....” (Participant 5)*

### 5.8.2.3 Educational and occupational difficulties: ‘I was bullied a lot and I was behind on work and teachers didn’t seem to understand’

Difficulties encountered in education were reported by half of the participants as having a negative effect on their attitude towards school and college and subsequently their motivation to persevere:

*“I didn’t want to, I didn’t like school, I didn’t have a good experience at high school ... I got bullied a lot and I missed a lot of school and, and I left in year 10 ... So I didn’t stay full term at school anyway ‘cos I was bullied a lot and I was behind on work and teachers didn’t seem to understand.” (Participant 1)*

One participant recalled how by the time help came in school, it was too late; he hated school and was no longer willing to listen:

*“They just, help came at the end but I’d lost” ... “I’d already gone then and I was a, I hate school, I hate you, I hate everybody and I wouldn’t listen to them really.” (Participant 2)*

Another participant reported falling behind and knowing he had to work extra hard to catch up influenced his decision to leave college:

*“I like was really far behind and it just got to the point where well I’m not exactly enjoying doing this course and I’m, I’ve now got to work extra hard so I don’t see the point to that.” (Participant 3)*

Several participants (2/6) reported their knowledge that recurrent absence due to illness and treatment would necessitate hard work and more years spent in education trying to catch up had put them off education:

*“I mean just over a month’s work is a lot of work, I mean it would have been doable but you know there was a good chance I was going to be missing a lot of dinner and a lot of overtime and stuff at college.” (Participant 3)*

*Interviewer: “So what do you think the main thing that stopped you was it?”*

*“I’d have probably gone on with it, knowing you know ‘cos I didn’t necessarily have to do it as a job so I could have just gone with the qualification and learned some extra techniques and stuff so, I’d definitely say being ill for all that time and then knowing I had to catch up so much.” (Participant 3)*

*Interviewer: “So overwhelming?”*

*“A big put off, yea so I’d say that’s definitely more of a factor than the other one.” (Participant 3)*

One participant specifically reported he wouldn't return to education unless organisationally things improved; though believed it never will:

*“No not unless you know stuff greatly improves which it never will because it's just that kind of thing. It's one of them things it's like if it was like a to do list it would probably be right far down you know ....” (Participant 3)*

For one participant, experience of CF-related prejudice and discrimination had put her off seeking employment:

*“She said oh it wouldn't be ideal, I said why, she said working in a hairdressers. I said but why's that, she said it will affect your chest and we don't want you coughing all over the customers. So I was right mad then and I said but it shouldn't be like that and then we started arguing so I just left cos I was just made to feel right uncomfortable” ... “And that, just that put me off, I just didn't, I just didn't want to ....” (Participant 1)*

#### 5.8.2.4 Self-efficacy: 'I'm poorly all the time I just think oh god I'm not ever going to get anywhere with this'

Participants' (5/6) beliefs in their abilities to succeed (self-efficacy) also proved influential in their motivation to persevere with education and employment. One participant recalled she left education because she thought if they continued to have periods of absence she would struggle to finish as educational difficulty increased:

*“Yeah 'cos I thought if AS levels and I'm struggling a bit to keep up if I have time off during A levels then 'cos the work is usually double then I'm really going to struggle to actually finish them.” (Participant 5)*

Half of the participants (3/6) specifically spoke of their failed attempts at trying to succeed in education and employment:

*“Yeah it’s like you get so far, you hit a brick wall, you’re back to square one again ....” (Participant 3)*

*“I did apply for jobs but never really got anything back.” (Participant 5)*

Because of this, the majority of participants (4/6) reported thinking they are never going to get anywhere:

*“I just think I’m never going to get anywhere. I always think well am I going to be able to be a midwife or you know because I’m poorly all the time I just think oh god I’m not ever going to get anywhere with this.” (Participant 1)*

*“It got to a point where you know it just wasn’t good experiences from colleges and it was like it felt as though it was going to be a case of yea I’m never going to get this qualification I need you know because I’m always ill or whatever so I don’t even see the point in trying another year.” (Participant 3)*

One participant specifically stated as he reflected on his hopes to be a games developer ‘I’ve realised it’s not happening.’

A lowered belief in ability to achieve an education and employment was reported by half of the participants (3/6) to have stopped them trying:

*“I just put myself in like a spin, they won’t employ me so I’m not bothering and that’s what I got into really.” (Participant 2)*

*“I think it’s more to do with experiences and it’s usually, I mean like that for instance it’s because of CF that all that happened and then through experiences like that it’s just like why do I bother?” ... “I’m now it’s to a stage where it’s like, you know, great. I may as well just not bother so.” (Participant 3)*

Another stated he felt there were no options available to help him try and return to education:

*“I don’t know, ‘cos, I don’t think there’s any options available to me, like say being tutored at home, I don’t think, yeah none of that’s really an option.”*

*(Participant 6)*

Several (2/6) reported the only way it would be possible to obtain an education would be to ‘self teach’ from home. Similarly, they both reported the only way they could be employed would be to ‘build and grow a business’ from home:

*“I want a career but I’m realistic and I’m brutally honest with myself and you know I don’t, ‘cos I’ve got GCSE’s up to my name, that’s it, it’s not, unless I was to kind of build and grow a business myself, that’s the only way around it I think.”* (Participant 6)

#### 5.8.2.5 Disease mastery: ‘I don’t think it would be good for me to go back yet while my condition’s not stable’

Disease mastery (participants’ perception of control over their disease) appeared to influence several participants’ (2/6) motivation to persevere with education and employment. One participant specifically spoke of how she didn’t want to return to education until her CF was stable and under control as she didn’t want to fall behind:

*“I don’t think it would be good for me to go back yet while my condition’s not stable because I’d be still having a lot of time off and I don’t want to get behind on my course ...”* (Participant 1)

Another participant described that as an adult, he didn't have time to go to work because of the demands of CF. He recalled how he felt he already had a job; it was 'called surviving':

*"Yeah to me it feels like when people are going on about oh wouldn't you want to work it's like I've got so much to do you know" (Participant 3)*

*Interviewer: "OK so you feel like you've already got a job?"*

*"Yea exactly it's called surviving so it's really not that easy at all..." (Participant 3)*

#### 5.8.2.6 Fears around the future: deteriorations in health and life expectancy 'It's like staring down the barrel of a gun'

The majority of participants (4/6) reported fears that being in education and employment will lead to deteriorations in health and ultimately reduce their quality of life. Participants' recalled how they felt attending education or work would 'risk a lot.' One participant spoke of his concern that should he become unwell he feared 'it would take everything away' from him, another explicitly described how because of these fears, he 'wouldn't dare work':

*"Everything that you do whether it be employment or whatever it's always going to have a toll on it so." (Participant 3)*

*"Granted you can do it but it's going to suffer, you know your health is going to suffer more depending on what you do and don't do ...." (Participant 3)*

*"I don't know again because like, is being in a college full of people, is that giving me colds and stuff and that's making me ill and come into hospital or, and especially, I'm at the level of lung function now where I can't really afford to lose anymore and, you know I struggle enough as it is you know, I can't, you know I can't play football or anything like that but, so it's almost like, is it going to 'cost me freedom if I go back to college." (Participant 6)*

One participant specifically spoke of how this had put him off employment:

*“I’m really put off employment as it is because I use like this Cystic Fibrosis forum that’s, there’s people, you’ve generally got 2 types of people you’ve got people like me who want to you know actually survive you know live long enough to enjoy life and then you’ve got people who have been brought up where if you don’t work then you’re the devil and these people who just work they’re on the transplant list and they’re like younger than me and stuff and it’s like how’s that a life to live.” (Participant 3)*

He reported the only way people with CF can manage to go to work is to miss medication, though he also described how this eventually catches up with you:

*“All these people everyone who work pretty much, they all skip medication because they’ve got to get to work on time and stuff... or they’ll work overtime and they’re just not concentrating because it’s like you’ve got ... you’ve got to do so much through the day, you know but all that stuff they’ll be missing and eventually it’s going to you know really come crashing down all this missing medication.” (Participant 3)*

Due to these fears and concerns, several participants (2/6) reported they have to weigh up, living life or staying alive; one participant spoke of how he struggled with this:

*“So it’s, you know it’s that kind of its weighing up living and being alive, that’s really what it is, the struggle between those two things. Living, going to college, doing what you enjoy but if it ‘costs you health then is it worth it?” (Participant 6)*

Several participants (2/6) also spoke of how an awareness of reduced life expectancy had led to doubt and lowered expectation that their aspirations would be achievable (Core Category three, subcategory 3.3). Doubt and lowered expectation of achieving aspirations were reported to have influenced their motivation to persevere with education and employment. One participant recalled as an adolescent she didn't go to University due to fears she wouldn't live to use her training:

*“I don't want to go to university to be a doctor and be there for 8 years and not be able to use, you know what I mean, like use my training ....”*

*(Participant 4)*

Fears around deteriorations in health and reduced life expectancy however, were reported by another participant as having a more complex influence on his motivation to persevere in his efforts at education and employment. Participant six who reported he was scared to think about the future and as a result had no expectations of achievement (Core Category three, subcategory 3.3) spoke of how he didn't work towards the attainment of his aspirations because he wants to enjoy himself:

*“It's difficult because I'm from a really professional family we're a kind of middle class sort of high achieving family and those aspirations are there but I'm honest with myself about it if you know what I mean, I kind of, I don't, it's difficult, I won't, I'd love to be successful but I don't expect it. I don't plan for it, I don't necessarily work towards it because I sort of think I just, I've got enough on, not enough on but I kind of, I just want to enjoy myself now ....”*

*(Participant 6)*

He spoke of how experience of being unwell had changed his perception of what is important in life:

*“Matures you, sobers you makes you kind of appreciate, well not appreciate what's important but changes your perception of what's important absolutely.” (Participant 6)*

He recalled that when he failed his first year at college due to being unwell he began to think about what was more important to him. In his second attempt at college therefore, he chose to drop the more academic subjects and choose those he enjoyed more:

*“I think maybe the only thing that came out of that failed first year was thinking well slightly more what’s important, what do you enjoy.” ... “So I think that’s maybe why I kind of ditched the more academic stuff.”*

*(Participant 6)*

However, as he grew older, he spoke of how compared to staying alive, he realised education was not that important:

*“Yeah and I think, yeah CF has made me just just, yeah realise that compared to staying alive, education’s not really that important.” (Participant 6)*

He spoke of how being unwell and knowing that this would happen again had led him to focus on the things he considers more important, such as himself, relationships and family:

*“I think when, when it puts you in such a compromised position and you know, and you come out the other side but you know what put you there is still there and can do it again and will do it again one day, you just sort of, I think you sort of think, I think it just makes, it sort of crystallises things in your head and things become clear about what I consider to be important which is primarily pleasing myself and you know, yeah and just yeah, relationships and family and stuff.” (Participant 6)*

This change in priority was specifically described as influencing his decision to leave employment:

*“Oh that was horrible, that was about 3 weeks I lasted there, just horrible, again though, and I think, I think at that point even, things were starting to form in my head ‘cos I just thought this isn’t worth my time if you know what I mean because it, I just hated it so much, it just wasn’t really a priority I just thought sod it you know, yeah.” (Participant 6)*

He reported that as an adult, he wanted a job but was not prepared to do something he didn’t enjoy because his time was too important to him:

*“I’d love a job but I’m not prepared to do something that I don’t enjoy because my time’s too important to me really.” (Participant 6)*

This participant also spoke about a more complex influence of CF; an absence of ambition. He recalled how because he had never ‘really achieved anything in life’, ‘never sort of set a goal, worked towards it and achieved it’ he now didn’t have any ambition:

*“I don’t have any ambition really I don’t think because I don’t think I’ve ever really achieved anything with my life if you know what I mean. I’ve never sort of set a goal, worked towards it and achieved it I don’t think.” (Participant 6)*

In adulthood however, participant four who as an adolescent had decided not to go to university due to fears she wouldn't live to use her training, reported a reappraisal of life expectancy and the presence of a belief in a future in adulthood had motivated her to continue with her aspirations for education and employment. She reported as an adult having a strong belief in the future and a belief she can succeed in what she wants to do. She described being able to put her fears and concerns to the back of her mind whilst telling herself that CF doesn't have to affect this:

*“Now like I think about my future, I just think well, like everything I want to do and I want in it, I know that I can have and like my CF doesn't really affect it I can put it to the back of my mind 'cos I think well it's not like a big thing overall like you know what I mean?”(Participant 4)*

She appeared to have an acceptance of her reduced life expectancy and spoke of how this would not impact on how she lived her life today:

*“But now like I'm older, like I obviously look like at anything that I want to know about CF, I know now because I've asked doctors and like I've said oh, am I really poorly and they went no like you're quite healthy for your age and things. They obviously don't want to say to you oh yeah you've only got so long to live and they can't say that obviously 'cos they don't know but like now I just think well I wouldn't be bothered anyway like whatever they said I wouldn't change like what I do tomorrow if they said I only had a year to live or like 20 years to live, it wouldn't make a difference to what I did tomorrow.”*  
(Participant 4)

At the time of interview this was the only participant who was actively planning to return to education and employment (Core Category four, subcategory 4.1 and 4.3).

## Core Category 6: Reflections on the Life Lived so Far

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The final core category describes participants' reflections on the life lived so far. All participants contributed to this. It contained four subcategories: Attainment of aspirations; Life could have been different; Living with regret; and Needs and Improvements.

### 6.1 Attainment of aspirations: 'I can't just go and be what I want to be'

All participants described how CF had prevented them from achieving their educational and occupational aspirations for life. One participant specifically recalled how 'basically, you try and go down that route and it just doesn't work out well'. Participants' reported how CF had stopped them from doing what they wanted to do in life. One participant described how CF had prevented her from 'being able to study what I want' whilst another reported 'not being able to get the job you want' and 'not being able to do stuff you want.' Several participants (2/6) reflected on how they couldn't attain their hopes of achieving a career such as being in the army because of CF, whilst another described CF had taken him off the 'treadmill' and 'conveyor belt' of education and employment:

*"I wanted to go into the Army and I didn't realise that you couldn't go into the Army if you had CF" ... "But when I like wanted to apply, then I did realise that so that stopped me applying for the Army." (Participant 4)*

*"How has it affected my career? Well it's kind of meant that I don't have one and probably never will have one because it has taken me out of it's sort of taken me off the treadmill really" ... "The conveyor belt of you know, school, college, Uni, degree, job, so it's kind of taken me off that and put me next to it if you know what I mean so I'm not really on that conveyor belt ...."*  
(Participant 6)

## **6.2 Life could have been different: ‘What I thought my future was going to be like. It’s not like it at all’**

Several participants (2/6) specifically reported how they thought their lives would turn out differently:

*“From when I was younger and like hopes that I had when I was younger and like what I thought my future was going to be like. It’s not like it at all”*  
(Participant 4)

One participant stated how she was now ‘unable to work due to health’ and this was ‘a very big difference’ to what she ‘would have liked to be doing:’

All participants reflected on how without CF, their lives could have been different. One participant described how if he hadn’t had CF he would have been able to sit his GCSEs and ‘stuff could have gone differently education wise:’

*“I probably would have continued or gone back to education at some point and studied and then gone to possibly Uni.”* (Participant 5)

Another participant reported how if she hadn’t had CF she would have been able to ‘join a college course and know’ she is ‘going to be there.’ Participants also spoke of how they would have had careers if it wasn’t for CF:

*“I think I would have had one, I don’t think I would have enjoyed it but I think I would have had one by now if it wasn’t for CF.”* (Participant 6)

One participant specifically stated ‘I probably would have been in the army by now’ whilst another stated that if it hadn’t been for CF she would have been doing something that she ‘really wanted to do from being young, rather than having to work round CF’ and what she is able to do.

### 6.3 Living with regret: ‘I wish I’d, I wish I had like been bothered’

All participants reported educational regrets. Several participants (2/6) recalled how they wished they had made school more aware of their CF and the difficulties they had encountered. One participant stated how she ‘kept a lot of it from the teachers’ whilst another reported ‘they knew I’d got CF but they didn’t know what it affected me with’. One participant in particular, spoke of his regret at not ‘teaching school’ about his CF and reflected on what he wished he had done:

*“I’d go in and tell them, I’d say look I’ve got Cystic Fibrosis, I’m going to be away all the time, even if you just have somebody bring me my homework or at least change, I mean, I don’t know just when, one to one’s and stuff like that.” (Participant 2)*

The majority of participants (4/6) described how they wished they had worked harder in education. Participants reported wishing they had ‘put slightly more effort in’ been ‘a bit more determined’ and ‘tried harder’. One participant reported how she wished she had been more committed in college as this would have enabled her to have become a doctor:

*“So, but now I think oh, I wish I’d, I wish I had like been bothered, because like I’ve done my access course and that was like really hard compared to my A levels and I just think, if I’d have been as committed as I was to this course as I was to my A levels then I would have been able to be a doctor or whatever I wanted to be so.” (Participant 4)*

Several participants (2/6) reported wishing they had stayed on in education whilst another reported a wish she had returned:

*“I had to leave half way through my level 2 because I wasn’t well at all and I just didn’t end up going back, I wish I had of done now though.” (Participant 1)*

The majority of participants (4/6) also described having occupational regrets. One participant described how employment could have waited stating he wished he had gone to college and achieved better qualifications instead, whilst another wished she had sought a better job. In particular, one participant reported regretting he didn't look into apprenticeships:

*“I would have looked more at apprenticeships” ... “I think they're a great thing and I regret that they've died out a little bit.” (Participant 6)*

Some participants (2/6) also spoke of personal regrets. One participant reflected on how he wished he had been calmer and more accepting of his experiences:

*“It's like well thinking about it it wasn't really going to happen because of how it went so it's like it just be like a lot more calm about it you know” ... “That's what I'd tell to myself if I could talk to myself back then anyway.” (Participant 3)*

Another participant reported how she wished the way she thinks now had been the way she had thought as an adolescent, in that her fears around reduced life expectancy had not prevented her from going to University (Core Category 5, subcategory 5.8, subsection 5.8.2.6):

*“Now I'm like 22 and I think well if I'd have, if I'd have like had same thoughts that I'd got now, like I want to be a paramedic and that's definitely what I want to do, I could have already been a paramedic by now if I'd have thought of that, you know if I'd not have been thinking oh I don't want to go to University because I'm not going to live that long to like enjoy doing what I've doing but then I think well I've like 6 years ago and I could have, I could have been a paramedic now, so.” (Participant 4)*

Several participants (3/6) also reported a number of health regrets. Namely, that they hadn't looked after themselves better in their younger years and adhered to treatment:

*“Probably look after myself better” ... “Just be better with my tablets and when I went through my phase when I was younger when I was smoking I wouldn't have smoked 'cos I think that affected my chest a lot.”*  
(Participant 1)

One participant reported wishing she hadn't been as 'much of an arse and a rebel' when she was younger and she had listened to her doctors:

*“You think doctors are there just to nag you when you're little and stuff, you're like yeah whatever. No they actually, they actually know what they're on about strangely so that would be my advice to anybody, it's just do it. It's so much easier.”* (Participant 5)

#### **6.4 Needs and improvements: 'Just people being more aware and people being more understanding and giving us a chance'**

Several participants (2/6) reported a need for more people to be aware and understanding of CF and for people, especially employers, to give them a chance:

*“Just people being more aware and people being more understanding and giving us a chance 'cos I think some employers just soon as you say CF and aw well we might have time off and they're just like well, well that's no good.”*  
(Participant 1)

One participant reported the need for people to understand that it isn't their fault they are absent. Another participant specifically mentioned the need for a better educational environment within hospital, stating it would be a 'be a bit better' to do work 'in a classroom instead of letting you do it on the ward'.

## CHAPTER V

### DISCUSSION

This chapter will first revisit the research design and aims of the study. A summary of the findings from the two linked studies is then presented and relationships with existing literature discussed. Methodological considerations are then examined followed by a discussion of the clinical implications and areas for future research. An overall summary and conclusion of the study will then complete the chapter.

#### **Revisiting Study Design and Aims**

The current study explored the educational and employment experiences of young people with Cystic Fibrosis and was carried out as two separate studies. Study one consisted of a cross-sectional survey undertaken in the Leeds regional Adult CF centre focussed on the educational qualifications and employment obtained by 162 people with CF. This contextual information was used to scope the background to study two.

Study two utilised the qualitative analysis of six interviews with young people with CF discussing their educational and employment experiences. The research aim was to explore young people's experience of education and employment and their understanding of the factors that influenced the development and attainment of aspirations. Using GT methodology, an overall theoretical model of participants' educational and employment experiences has been developed, highlighting possible influences on young people with CF and providing some speculations as to why many do not fulfil their potential. It is hoped that the findings of this study will contribute to the wider CF literature and literature on young people with other chronic illness.

#### **Summary of the Findings**

The aim of this discussion will be to present a summary of the findings in relation to the wider literature, with a focus on unique and novel contributions to the existing evidence base. An overview of the findings from study one and two will be presented separately.

## STUDY 1: EDUCATION AND EMPLOYMENT SURVEY

### Educational Attainment

The 162 people that took part in the survey were almost all diagnosed in infancy (88%) and reflected a wide age range (range 17 to 69 years). Over half (59%) had left school before the age of 18 years and 97 (64%) reported their highest educational qualifications were obtained during school or college. Only 28% had attained educational qualifications at degree level, lower than the figure for the UK population, which has been between 35-39% since 2000 (OECD, 2011).

This survey, then, provides evidence that educational attainment in people with CF is below the national average, and supports the findings from two UK CF population surveys carried out by Walters et al. (1993) and Huq et al. (2011). It has echoes too in research on other chronic illnesses: childhood survivors of renal failure and cancer have also been found to have lower levels of educational attainment than those in the general population (Morton et al., 1994; Lancashire et al., 2010). In contrast, some research has suggested that the educational attainment of people with CF is similar or possibly higher than the general population (Walters & Warren, 2001; Laborde-Castérot et al., 2012). Again, there are findings in the literature on other chronic illness which support these findings. In particular, childhood survivors of diabetes mellitus and juvenile arthritis have been found to show no educational impairment (Jacobsen et al., 1997; Peterson et al., 1997).

Explanations for the differences between the current survey and that of Walters & Warren (2001) and Laborde-Castérot et al. (2012) are not obvious. The latter study is French and therefore reflects a different education system, but the Walters and Warren (2001) study is the latest in a number of surveys carried out in the UK which appears to reflect increasing educational attainment in young people with CF, perhaps because of educational reform or improved health. This does not appear to be true in the current study, but there are important methodological differences: the current study focussed on one large CF unit, inviting people to participate in person during their routine clinic attendance whereas the Walters and Warren study is cross site and involves a postal survey, different factors may therefore be influencing the decision to participate in the two studies so the samples may not be the same. The findings of the current survey therefore should be interpreted with caution.

## Employment

At the time of the survey, 89 (55%) participants were in current employment; 29% fulltime; 21% part-time, 1% voluntary and 4% studying and working. This is significantly lower than the employment rate for the UK population, which for all 16 to 64 year olds is 70.4% (OECD, 2008).

Findings from the current study are consistent with the rates of employment from other studies conducted in CF populations in the UK: 54% of 866 people (Walters et al., 1993); 47% of 1245 (Walters & Warren, 2001); 48% of 2827 (Cystic Fibrosis Trust, 2004a); 40% of 92 (Huq et al., 2011); and 52% of 100 (Nash et al., 2011). They also support the findings of studies conducted in CF populations in other countries: 56% of 130 people in Canada (Frangolias et al., 2003); 48% of 183 in California (Burker et al., 2004); 72% of 50 in Australia (Hogg et al., 2007); 55% of 670 in Germany (Besier & Goldbeck, 2011); and 70% of 207 in France (Laborde-Castérot et al., 2012). It seems clear, then, that people with CF have lower occupational attainment than those in the general population.

The majority of participants (82%) in the current study received some level of regular benefit. The most common was Disability Living Allowance (DLA) with 79% of the sample receiving this. These findings support the evidence from two recent UK CF population surveys who found 96% (Nash et al., 2011) and 83% (Huq et al., 2011) of their respective samples claimed one or more benefit, and that DLA was the most common benefit received.

Classification of occupation in the current study found 26% of the 55% who reported current employment were in professional occupations and 27% were in intermediate occupations. This is similar to the French CF cohort survey which found 25% of the 70% in current employment were in professional occupations, yet, 39% were reported to be in intermediate occupations, somewhat higher than that found in the current study (Laborde-Castérot et al., 2012). Findings should be interpreted with caution as the criterion used to classify occupations is likely to have differed between studies. An explanation for these findings may be that unskilled professions are more likely to require a level of physical strength and present a number of environmental risks which for people with CF may cause difficulty. In addition, it may be that people from higher socioeconomic classes are protected from the impact of CF on education, which enables them to succeed in gaining professional occupations. Further discussion on this topic will take place in a later part of this chapter.

## **Factors Predicting School Leaving Age, Educational Attainment, Employment and Perceived Impact of CF on Education and Career**

### ***Age***

No associations were found between age at the time of the survey and school leaving age of 18 or over, educational attainment at degree level and employment, which indicates that cohort effects are not related to the findings i.e. changes in secondary and higher education over the past twenty years. Few studies in the literature to date have examined the relationship between current age, school leaving age and level of educational attainment in people with CF. A consistent finding within the CF literature however, is that the older an individual is the greater the number of hours they are likely to have worked (Gillen et al., 1995; Hogg et al., 2007; Demars et al., 2011). Not all studies have found this relationship however: work status was found to be unaffected by age in the French CF cohort (Laborde-Castérot et al., 2012). Although findings from the current study support some of what is reported in the CF literature, research examining the relationship between age and work status in people with CF remains conflicting and therefore should be interpreted with caution.

### ***Sex***

No associations were found between the sex of participants and school leaving age of 18 or over, educational attainment at degree level and employment. The age at which participants left school, ability to obtain a degree and work status therefore, were all found to be unaffected by sex in the current study. Although rarely studied, there is some research which suggests female sex is an independent risk factor for CF work disability (Burker et al., 2004). A recent UK CF population survey in particular, found significantly more females than males (23% versus 13%) to be neither employed nor in education (Nash et al., 2011). However, not all research has found this relationship: work status was found to be unaffected by sex in the French CF cohort (Laborde-Castérot et al., 2012). Findings from the current study, although they support some of the findings reported in the CF literature should be interpreted with caution, as research examining the relationship between sex and work status in people with CF remains conflicting.

### ***Level of educational attainment***

No association was found between level of educational attainment (highest qualification) and school leaving age in the current study. However, level of educational attainment was found to be a significant predictor of employment, although the variance explained was small. The higher participants' educational qualifications therefore, the more likely they were to be in employment. This confirms the findings from the UK CF cohort survey by Walters and Warren (2001) and that of the French CF cohort survey by Laborde-Castérot et al. (2012) who like the current study, found educational level to be a strong predictor of employment in people with CF. To improve the employment prospects of people with CF therefore, we must intervene in education.

### ***Disease severity***

No associations were found between current FEV<sub>1</sub> (an index of disease severity) and school leaving age of 18 or over, educational attainment at degree level and perceptions of the impact of CF on education. There is little research which examines the relationship between CF disease severity and school leaving age and perceived impact of CF on education. However, there is evidence that people with more severe CF disease are less likely to achieve educational qualifications (Walters et al., 1993), which is logical. A possible explanation for the lack of relationship between disease severity and level of educational attainment in the current study is that the measure of FEV<sub>1</sub> is contemporary and therefore does not tell us about disease severity in childhood.

A significant association was found between current FEV<sub>1</sub> and employment in the current study, though the variance explained was small. Participants with more severe CF disease therefore were less likely to be in employment, supporting the findings of Laborde-Castérot et al. (2012). The current study found a significant negative association with current FEV<sub>1</sub> and perceptions of the impact of CF on career. Participants with worse CF disease therefore, perceived greater impact of CF on their career. With findings that those with worse CF disease are less likely to be employed, it makes sense that those with worse CF disease perceived greater impact of CF on their career. This supports the findings of an American study of 68 employed people with CF who found those with increased disease severity were more likely to agree with the statements 'CF impacts my chances of getting a job' and 'balancing employment and CF care is stressful' (Demars et al., 2011).

It is important to acknowledge there is some doubt in the literature surrounding the use of FEV<sub>1</sub> as a valid predictor of work disability. Although Laborde-Castérot and

colleagues (2012) found FEV<sub>1</sub> to be significantly associated with work status, risk was not found to increase linearly as lung function decreased. Burker et al. (2004) also found no difference in FEV<sub>1</sub> levels between employed and unemployed people with CF. In the current study an interesting observation was the large amount of variability in FEV<sub>1</sub> levels and employment. Several participants who reported they were not in employment and perceived the impact of CF on career to be great were found to have relatively healthy lung function levels, whilst several of those who reported being in employment had poor lung function (low FEV<sub>1</sub> levels). These observations not only corroborate the ongoing doubt regarding the use of FEV<sub>1</sub> levels as a valid predictor of CF work disability, they clearly highlight the complexity of workplace participation in people with CF and the importance of the *perceptions* of the person with CF.

### ***Socioeconomic status***

Socioeconomic status in the current study was the factor most predictive of school leaving age and educational attainment at degree level. As is true of the wider population, the lower the participants' socioeconomic status the more likely they were to leave school at a younger age and the less likely they were to achieve educational qualifications at degree level. The overall numbers are lower in the CF population than in the general population, however. The relationship between socioeconomic status and educational attainment in people with CF has not been the focus of much research. Yet there has been some research which echoes that of the current study: Walters, Briton and Hodson (1993) found people with CF from manual social class backgrounds were less likely to leave school with educational qualifications and be in employment. Whilst a number of environmental factors such as parental and school influences are likely to have contributed to the current findings, the role of CF appears influential. In the current study, those from lower socioeconomic backgrounds reported greater impact of CF on their education and career. It seems therefore that those in the middle classes are in some way protected from the impact of CF, which enables them to succeed in education, which in turn, opens up opportunities for employment; a possible explanation as to why a high proportion of people with CF who gain employment end up working in professional occupations.

Socioeconomic background is influential in the attainment of educational and occupational success in people with CF: those therefore, with less financial security appear at a disadvantage. To improve the educational and employment prospects of people with CF it is imperative that this group of individuals is specifically targeted.

***Perceived impact of CF on education and career***

Participants' perceived impact of CF on their education and career were bimodally distributed and significantly related to each other. Those participants therefore who perceived CF to have impacted on their education to a great extent also perceived CF to have impacted to a great extent on their career. Findings suggest that those who experienced difficulty in education also experienced difficulty in employment. It seems likely therefore, that participants' experiences of employment were affected by their experiences of education. This not only supports the findings in the current study and that of the existing evidence base which shows educational attainment to be a strong predictor of employment, it supports that of the qualitative findings from study two. No associations however, were found between perceived impact of CF on education and career and school leaving age of 18 or over and educational attainment at degree level.

**Overall Summary**

Findings from the current study suggest educational and occupational attainment of people with CF to be below the national average and support that of the existing evidence base. Echoing that of other research, CF disease severity and level of educational attainment (highest qualification) were the factors most predictive of employment. Of particular interest however, was the role of socioeconomic status; the factor most predictive of school leaving age, educational attainment at degree level and perceived impact of CF on education and career. It is apparent therefore, that people with CF with less financial security may be disadvantaged in terms of achieving educational and occupational success.

The survey supported the conclusions of existing research: that people with CF still lag behind the general population in terms of education and employment. The reasons for this are not clear, though socioeconomic status seems to be related. One possibility is the protective effects of higher income. Alternatively, it may be that the aspirations of young people with CF remain limited, despite advances in treatment and life expectancy.

To explore these ideas further, study two explored the education and employment experiences of six young people with CF (age range 21 to 24 years), all of whom were currently not in higher education or stable employment.

## **STUDY 2: A QUALITATIVE STUDY OF EDUCATIONAL AND EMPLOYMENT EXPERIENCES**

The first theme from the qualitative study set the context for all the other themes: all participants reflected on what it is like to live with CF. For most, CF was described as a 'part of life' that they have become used to, yet it is clear that this life is not without its difficulties. Recurrent experiences of being 'poorly' and 'in and out of hospital' throughout their lives were described by all participants. The hidden, unpredictable and restrictive nature of CF was described and for many, reported as a challenge. A developmental aspect in the context of CF was also discussed. Participants spoke of how their knowledge, understanding and awareness of CF and their responsibilities for self-care increased with age. Taking on this responsibility in adolescence, for some proved difficult, and management of CF was reported by several to have 'turned to chaos.' With increasing age and maturity however, the realisation of the need to adhere to treatment and the positive effects of doing this were reported by all participants.

### **Development and Attainment of Aspirations**

All participants reported the early presence of aspirations and hopes for life. The majority recalled that in early childhood and adolescence they had hopes of going to school and college and gaining qualifications. Similarly, most recalled childhood ambitions about what they wanted to be when they grew up, though the majority commented on how these had changed throughout their lives. Other hopes for the future such as to 'travel' 'move abroad' and meet someone and get married were also described. Hopes for health and wellbeing in both childhood and adulthood were also salient. As an adult, one participant specifically spoke of his hopes to live to 40 years and older.

The aspirations they held as children had their origin in various personal interests. Several participants recalled wanting to work with children because they 'love' and 'adored' children, whilst another spoke of his interest in weapons and warfare had shaped his desire to join the army, for example. Familial influences were also important to some, particularly in choice of career, for example a desire to follow in the professional footsteps of particular family members. For some, CF emerged as an influence on the creation of aspirations, for example a desire to become a nurse fostered through exposure to hospital environments, to care for others the way they had experienced care themselves.

As became clear later, however, the childhood aspirations that they described were rarely fulfilled, and were often influenced and sometimes extinguished by having CF. Several participants reported how a growing awareness of their reduced life expectancy had 'restricted' their hopes and aspirations, for example. Although the continued presence of aspirations was reported, some expressed doubt and little expectation that these would be achievable which in turn, negatively impacted upon their attempts at attainment. One participant spoke of being scared to think about the future due to the uncertain and progressive nature of CF. He reported little expectation of achievement because of this, and as a consequence had 'stopped working towards' the attainment of aspirations.

Early aspirations of people with CF have not been a focus for much research. One study has suggested that children born with CF today have aspirations in line with their 'healthy' peers (Badlan, 2006), perhaps reflecting increasing confidence in treatment. A comparative study of people with and without disability by Burchardt (2005) reported similar findings. They found no differences between the aspirations of young people at 16 years of age with a disability (physical or sensory impairment or mental health problems) than those without (Burchardt, 2005). Regardless of disability, the majority of young people at 16 years of age aspired to stay on in education and pursue a professional occupation. Although no comparative group was employed in the current study, the aspirations voiced by the participants do appear in line with what might be expected from 'healthy' peers.

There are many factors reported in the literature to influence the development of aspirations, namely social class, peers parental expectations and personal resilience (Furlong, 1992; Schoon & Parson, 2002; Burchardt, 2005; Low, 1996) and some of these were mentioned by the participants in the current study. The biggest influence for the participants, however, was clearly their CF. Though rarely an explicit focus for research, there are echoes in other studies: in a recent American study assessing the current employment experiences and perceptions of the impact of CF, 22% of the 68 employed participants reported CF had affected their choice of occupation (Demars et al., 2011).

Aspirations are a critical ingredient in the achievement of educational and occupational outcomes later in life (Burchardt, 2005). Whilst many young people fall below their educational and occupational aspirations in early adulthood, research from the disability literature suggests the gap appears wider for those with disabilities (Burchardt, 2005). A possible explanation absent in the CF literature, is that disabled people are not always encouraged to see themselves as having valuable roles to play in adult society, which translates into unduly limited aspirations; without self-belief and

encouragement aspirations are all too likely not to be attained (Wilson, 2003; Burchardt, 2005). A Norwegian study examining level of hope in 86 people with CF, found those with CF scored higher on the item 'scared to think about the future' than those in the general population (Rustøen et al., 2004) and our participants seem similar. The optimism generated by the development of new medical interventions does not seem to be shared by them. With medical advances in treatment having only increased longevity over the last decade, the prospect of a future is still new and for some, adjusting to this 'extra' time may be difficult as many may be scared to believe in it (Badlan, 2006). In the current study, limited belief in a future lowered belief and expectation that aspirations could be achieved which in turn, influenced their attainment, a finding echoed in the disability literature, yet unique to the developing CF evidence base.

### **Educational and Employment Experiences**

All participants provided rich and reflective accounts of their experiences of education and employment. All reported experience of attending school and college and the qualifications they obtained. Comparative accounts of not achieving the qualifications they had aspired to were reported by all participants. Reflecting on their time in education, many recalled wishing they had worked harder and several reported regrets they had left and not returned. All but one participant reported experience of employment; again, experiences of employment did not meet the aspirations of childhood. The presence of regret was again apparent, namely a regret they had not sought a better job and in some cases wishing they had not pursued employment and carried on with their education instead.

### **The Influence of CF**

All participants reported how CF had been instrumental in preventing the attainment of educational and occupational aspirations. Accounts of how CF had stopped them from doing what they wanted to do in life were voiced, many recalling how because of CF they had not been able to study what they wanted and get the job they had wanted. One participant specifically spoke of how CF had taken him off the 'conveyor belt' of school, college, university and employment. All reflected on how life could have been different without CF. They spoke of how the attainment of educational qualifications and having a career would have been possible. A complex interaction between CF and the environment,

influential others and the self, shaped participants experiences of education and employment.

***CF and the environment: practical and physical consequences of CF***

A number of practical and physical consequences of CF were reported by participants to have impacted on their experiences of education and employment. A developmental trajectory of CF intruding on education was described: as participant's aged and educational difficulty increased, the negative influence of CF became more pronounced. Repeated absences from education because of CF were described by all participants across their education, resulting in them falling behind in class and having to try and catch up when they returned. Unexpectedly, absences caused by illness were not always the only – or even the major – cause of problems, the routine appointments at the CF clinic were noted as causing continual problems in staying on top of school work. Difficulties coordinating the necessary work they needed to try and catch up, especially as educational difficulty increased, proved particularly challenging. Differing educational expectations of school and hospital also impacted upon this: some reported an expectation by their school that they continue with their studies in hospital, yet others reported little expectation and little coordination between school and hospital, recalling how 'you just get it into your head' that 'I'll do this today instead of my work'. Over time, continued absence from education and the difficulty experienced trying to catch up, resulted in participants slowly falling further and further behind in their education. A gap between participants and their peers also slowly widened with reports that recurrent absences from education led them to feel they were losing their footing socially. All recalled how CF had impacted on their opportunities to achieve educational qualifications. Whilst for most this had been largely outside of their control, several acknowledged the part their deliberate non-adherence to treatment in adolescence had played.

In employment, having to manage repeated absences because of CF was also reported. Difficulties maintaining fulltime employment and in one instance missing an interview because of CF were described. Trying to balance the demands of education and employment in conjunction with a demanding treatment regime for most proved a challenge. One participant specifically felt his employability was limited by the requirements of CF as he reported it was unlikely any one company would be able to support all his requirements.

School absenteeism in children with CF has long been known to negatively influence educational performance (Fowler et al., 1985; Grieve et al., 2011) and our

participants reported similar experiences. Although insight and understanding into the experiences of education in people with CF has rarely been the focus of research, there are echoes in other studies: an American qualitative study exploring the influence of peer relationships on adjustment to CF in adolescence found an increase in CF disease severity disrupted peer relationships, school attendance and ability to keep up with school work (D'Auria et al., 2000). Similar themes of 'being out the loop' and feeling 'out of place' on their return to school were also reported. Few studies have reported the developmental aspect of CF on education and the increasing obstacles faced by young people trying to catch up as they move into secondary school, a contribution of the current study to the developing evidence base.

Again little research has explored the employment experiences of people with CF, though like our participants, absences from work because of CF have been reported in the literature: 47% of 68 employed participants with CF in an American study reported missing work because of CF (Demars et al., 2011). The notion that employability is limited by the presence of CF as mentioned by our participants has also been reported in the literature. In the French CF cohort of 207 participants, 55% reported feeling limited in their job because of CF and 67% specifically stated CF had prevented them from having a career (Laborde-Castérot et al., 2012).

There is some research which suggests people with CF experience difficulty fulfilling their aspirations as the demands of CF and the restrictions placed on them by its requirements increase (Badlan, 2006). Trying to find employment opportunities which are flexible enough to accommodate treatment regimes is a common challenge faced by people with CF (Edwards & Boxall, 2010) and was confirmed by our participants. Interestingly, there is some evidence which suggests difficulty fulfilling aspirations can lead some to reduce their self-care and adherence to treatment in a trade off between quantity and quality of life (Radley, 1994). Whilst non-adherence in adolescence of several participants in the current study echoes this finding, its impact on the educational attainment of people with CF remains relatively under reported, another unique contribution of the current study to the existing evidence base.

***The influence of others: alleviation and aggravation of the problems caused by CF***

It is clear that the practical and physical consequences of CF impacted upon the education and employment of participants; it was also clear, however, that the impact of this was moderated by the action of others. Feeling that their CF and the difficulties they had encountered in education were understood by teachers and tutors and receiving help and support in education, such as one to one sessions and (in one case) having a special team in school to help catch up were all reported as beneficial. Many however, reported no such provision. Several described how the educational setting was ignorant of the implications of CF. One participant specifically spoke of how the education system does not acknowledge 'a physical disability' which is 'more hidden'. A lack of understanding about CF was also reported outside of the education system, with several participants stating people, especially employers, don't know or understand about CF.

Whilst for some, the sympathetic and supportive actions of others helped alleviate some of the difficulties caused by CF; in some cases the actions of others made things worse. Some responses by education were reported as futile and in some cases detrimental. Perhaps to try and help catch up or perhaps because it was the only place available, participants recalled how they were put in a class with 'misbehaving' peers; another spoke of his failure to receive full curricular home tuition. The experience of CF-related prejudice and discrimination in both education and employment were also reported. Accounts of being bullied and victimised by peers and staff in education because of their CF were voiced. In employment, participants recounted experience of being dismissed from work and in some cases, refused employment explicitly because of their CF.

Provision of support and level of CF understanding in education has not been the focus of much research, though some of what is described in the current study mirrors that of the existing evidence base: in an American study many reported how peers and staff in school didn't understand the limitations of CF because many of the symptoms were not visible (D'Auria et al., 2000). A lack of understanding and ability of others to identify with these experiences were reported to have led participants to avoid talking about their CF (D'Auria et al., 2000). This may explain why several in the current study recalled they never spoke about their CF in school; in adulthood they regretted this and recalled how they wished they had made school more aware of their CF and the difficulties they had encountered. Absent in the CF literature however, are accounts of how problems in education can be aggravated by the direct and indirect discrimination and persecution of people with CF.

The notion that people with CF face prejudice and discrimination in the workplace has been remarked upon many times. There are reports in the literature of an overshadowing of abilities and qualifications and – as happened to our participants - the withdrawing of job offers once employers are informed of CF (Edwards and Boxall, 2010). In a UK study investigating the employment experiences of 33 participants with CF, 11 reported experience of discrimination, primarily the consequence of employers not understanding their condition (Langman & Brennan, 2008). In an American study of 68 employed people with CF, 31% of participants reported their absences from work because of their CF were problematic for their employers (Demars et al., 2011); again these findings echo that of the current study.

***The influence of CF on the self: persevere, or leave and not return***

The physical and practical consequences of CF and the influence of others illustrate the many practical and prejudicial barriers young people face in education and employment. All participants described how this had influenced their motivation to persevere in education and employment. Overall, two dominating narratives were observed.

On the one hand, participants described a narrative in which their CF had made them passionate about proving CF didn't have to hold them back and dictate their life, leading them to engage and persevere with education and employment despite the many obstacles. Whilst for one participant, this had served as motivation in childhood, in adulthood reality had proved more difficult. For another however, the opposite was described: she recalled as an adolescent that an awareness of reduced life expectancy had prevented her from going to University due to fears she would not live to use her education. In adulthood however, she spoke of having an acceptance of mortality and reported a strong belief in the future and her ability to succeed. She described being able to put her fears and concerns to the back of her mind whilst she told herself that 'CF doesn't have to affect this'. In adulthood, a reappraisal of life expectancy and the presence of a belief in a future in conjunction with what appears to be increased disease mastery and self-efficacy appeared to reignite a belief that educational and occupational aspirations can and will be attained. This participant was the only one actively planning to return to education and employment at the time of the interview.

The second more dominant narrative was less optimistic. It was one in which the strong perception was that CF had prevented them from achieving their aspirations, which had left them feeling despondent and hopeless in their efforts to persevere, leading them to

withdraw from education and employment. For some this appeared reactive: difficulties experienced in education and employment such as recurrent absences and associated setbacks, problems with treatment adherence, deteriorations in health and discrimination and prejudice were all reported to have had an adverse effect on motivation, with many citing this as the reason they left and have not returned to education and employment. Many described how their difficulties in school had an adverse effect on their attitude towards education, and subsequently their motivation to persevere with it. Failed attempts at trying to succeed in education and employment for many, had left them feeling like they are ‘never going to get anywhere’ and in some cases had stopped them trying.

For others, withdrawal from education and employment appeared proactive: based on a need to control and manage their CF, avoid illness and maintain their health. Several reported needing to gain control over their condition before they considered returning to education and employment. Fears surrounding the future, particularly issues of health and mortality, were also salient: several spoke of how they felt they had to weigh up living life or staying alive due to fears that being in education and employment would risk their health and ultimately their quality of life. For one participant, this resulted in an altered sense of priority: a focus on the things he considered more important such as himself, relationships and family led to a departure from education and employment. The consequence of this however, was he reported feeling that he had ‘never really achieved anything in life’ resulting in an absence of ambition.

The first narrative, then, describes how CF had in some circumstances, though not always successfully, increased motivation to persevere in education and employment. The second narrative however, features a withdrawal from aspirations about achieving employment and career goals, sometimes despondently as a reaction to barriers they had experienced and sometimes as a seemingly deliberate attempt to establish different priorities in life. In the latter case, this too sometimes seemed to follow negative experiences at school or college, and for some citing different priorities may be a reaction to impossibility of achieving alternative goals.

There are clearly very real issues in balancing health with work in CF. In one French CF cohort 71% of participants who received at least one antibiotic treatment in the last year reported stopping working because of this (Laborde-Castérot et al., 2012). Few studies however, have documented this relationship in education. Severity of disease and its influence on educational and workplace participation in people with CF is more widely known. Several studies echo the findings from the current study: in an American CF cohort

of adolescents, increasing disease severity was reported as causing many to drop out of school (D'Auria et al., 2011). In the French CF cohort 13% reported stopping their studies because of CF and in an American study 22% stopped work (Laborde-Castérot et al., 2012; Demars et al., 2011). Whilst the relationship between negative school attitude and school dropout is documented in the CF literature (Croll et al., 2008), few have explored the origin and development of the beliefs which arise as a result of these experiences, a unique contribution of the current study to the developing evidence base.

Lack of educational and occupational fulfilment has been reported in the disability literature as adversely impacting upon the confidence and belief that individuals can succeed in the labour market (Burchardt, 2005) and our participants seem similar. Degree of disease mastery and self-efficacy have been found to be powerful predictors of educational and workplace participation in people with CF (Bassi et al., 2007; Bandura et al., 2001; Goldberg et al., 1985). Echoing the findings of the current study, those with little belief in their abilities to control their disease and little belief in their abilities to achieve success are less likely to succeed in staying on in education or gaining employment (Grieve et al., 2011; Banks et al., 1992).

For young people with CF, maintenance of a positive outlook is important (D'Auria et al., 1996). There is some research to suggest that people with CF who are less fatalistic in their outlook are more likely to succeed in staying on in education or gaining employment (Banks et al., 1992), which is similar to the findings from the current study. Limited belief in a future has previously been linked to rethinking or redefining values, changing opinions about what is important in life (Sprangers, 2002; Cousens et al., 1988). There has been some speculation in the literature that this may be one explanation for lower rates of educational and occupational attainment in people with CF (Rustøen et al., 2004) and our study seems to support this. Interestingly, levels of hope in people with CF have been found to increase with age (Rustøen et al., 2004). Having lived with uncertainty about their life expectancy for much of their lives, reaching adulthood may feel like they have beaten the odds, giving them increased belief and hope in a future (Rustøen et al., 2004), this may be an explanation for the increased belief in a future reported by one participant once they reached adulthood. Those who have greater belief in their ability to shape their future are more likely to have higher aspirations (Burchardt, 2005), a finding echoed by the current study.

### **Overall Summary: Answering the Research Aims**

All participants could recall their childhood aspirations for education and work. They recognised several influences on these, including personal and familial influences, yet the biggest influence appeared to be CF. In early childhood the role of CF appeared almost benign, with participants recalling that regular trips to the hospital had influenced early career aspirations. With age however, the influence of CF turned more malign: for some, awareness of reduced life expectancy, lowered hope and expectation that their aspirations would be achievable, which in turn, negatively impacted upon their attempts at attainment.

Participants articulated with some emotion the difficulties they had encountered trying to fulfil their early aspirations. The influence of CF was clear: repeated absences from education and employment because of routine appointments, periods of ill health and adherence to a complex, time consuming and demanding treatment regime were all reported as problematic. On education there was also a developmental aspect: as participants grew older and the difficulty of their school work increased, the negative influence of CF on their ability to keep up with their school work became more pronounced. The more they missed education, the more they fell behind and the more difficult it became to catch up. This had an accumulative effect over time, with a gap widening both academically and socially between them and their peers.

It seems the actions of others in some circumstances helped alleviate some of the difficulties posed by CF. Understanding of CF and providing support and help in the education system appeared beneficial for some. However, in some cases the actions of others appeared to hinder success: accounts of being bullied, being put in a class with naughty peers and in some cases dismissal and refusal from employment because of CF were all voiced.

The physical and practical consequences of CF and in some cases the actions of others, illustrated the many practical and prejudicial barriers that prevented many from attaining the educational and occupational hopes they aspired to. The reality of struggles to achieve and maintain educational and occupational performance because of CF, and worries about their health and life expectancy had a significant impact on their self-belief and belief in educational and workplace providers. Limited aspirations and self-belief lowered expectations of achieving educational and occupational success, resulting in a withdrawal from aspirations and subsequent educational and occupational attainment.

### **Psychological Theory and Literature: Links with the Current Findings**

This next section describes and reviews the literature on two dominant psychological theories: Learned Helplessness and Attribution Theory. These theories are then discussed in light of the current study findings.

#### ***The theory of learned helplessness***

The psychological theory of learned helplessness was first developed by American psychologists Steven Maier and Martin Seligman in the late 1960's from their early laboratory experiments involving animals. They found that animals repeatedly exposed to an adverse stimulus which they cannot escape eventually give up trying to avoid the pain and behave as if they are entirely helpless. They found that even when these animals were presented with an opportunity to escape, their 'learned helplessness' prevented action; essentially they were helpless to effect any change over their situation (Maier & Seligman, 1976). This work was subsequently replicated in animal studies and later observed in humans. Watson & Ramey (1969) famously demonstrated learned helplessness in groups of human babies. They found that those babies who had no control over the rotation of a mobile, showed no attempts to control the mobile when later presented with the means to influence its movement. In essence, what these experiments demonstrated was that organisms that learn outcomes are uncontrollable by their responses can become paralysed by this knowledge, leading to the development of helpless behaviour (Maier & Seligman, 1976).

Whilst the presence of learned helplessness can take many forms, three major deficits are predominantly found: reduced motivation to respond to later aversive events with attempts to avoid or escape; a cognitive change whereby people exposed to an uncontrollable event believe the outcome of later events are independent of their own skill e.g. the presence of a belief that responding is futile. Additionally, ability to recognise success even when success has been achieved has also been found to weaken. Finally, many can experience heightened emotionality, predominantly feelings of anxiety and depression (Maier & Seligman, 1976; Miller & Seligman, 1975).

In summary, when an individual is faced with an outcome that is independent of their response, they can learn that the response and outcome are independent. The situation therefore can be perceived as uncontrollable and lead to the development of learned helplessness.

In the years following the development of learned helplessness the concept was linked with models of depression, and there was much debate in the literature surrounding issues of generality and chronicity. An issue raised was why did learned helplessness on some occasions generalise across situations and on others remain situation specific (Alloy, Peterson, Abramson and Seligman, 1984). To overcome this difficulty, in 1978 the theory of learned helplessness was reformulated to incorporate the theory of attribution. This next section will examine the basis of attribution theory and then revisit its amalgamation with the theory of learned helplessness.

### ***Attribution Theory***

Attribution theory is defined as the process in which an individual uses information to explain causal events; essentially, the explanation an individual makes to explain success or failure (Fiske & Taylor, 1991). The theory is underpinned by the notion that individuals are motivated by a desire to feel good about themselves. Thus, an individual's self-perception can influence the way in which success or failure is understood, which in turn, influences their subsequent attempts at performance (Heider, 1958; Weiner, 1980).

There are two key assumptions underpinning the theory of attribution: firstly, an individual will predominantly make sense of their environment in order to preserve a positive self-image. Secondly, the attributions or perceptions used to explain the success or failure will influence future effort and motivation to perform the task again (Weiner, 1980). For example, an individual who comes first in an English exam may attribute their success to their own ability and skill and therefore feel motivated to work hard and carry on with their studies in English. However, an individual who fails their English exam may attribute their failure to the poor teaching they received and therefore lack the motivation to persevere with their studies. In essence, success or failure will be attributed to factors that enable an individual to feel good about them self and depending on the outcome may positively or negatively influence motivation.

Researchers categorised assessments of success or failure along three different dimensions: internal-external, stable-unstable and controllable-uncontrollable. Internal factors are defined as those which reside within the individual, whereas external factors are those associated with the environment. Stable factors however, are defined as those that are likely to yield the same outcome if performed again, whereas those that are unstable are likely to produce a different outcome. Finally, controllable factors are those that an

individual believe they can alter, whereas uncontrollable factors are those that are perceived more difficult to change.

The notion of attribution theory has important implications for the achievement of academic success. Research has shown that students are more likely to persevere with education if they attribute their academic successes and failures to internal, unstable factors with which they can control e.g. level of effort, whereas, those who attribute success or failure to external, stable factors with which they cannot control e.g. intellectual ability are more likely to disengage.

***Learned helplessness reformulated: the amalgamation of attribution theory***

In 1978, Abramson, Seligman and Teasdale proposed that when an individual finds themselves helpless, the generality and chronicity of their helplessness is determined by the causal attribution made. The attribution made by an individual to make sense of a response and outcome that are independent determines their expectations for future response outcome, which in turn influences the generality, chronicity and potency of helplessness deficits. In essence, the attribution made predicts the likelihood of the expectation recurring and it is the expectation which leads to the emergence of helplessness deficits (Abramson, Seligman & Teasdale, 1978).

The amalgamation of attribution theory with the theory of learned helplessness enabled Abramson and colleagues to predict which situations and across what time, helplessness was likely to present. Evidence suggests that those individuals who attribute failure to internal, stable and uncontrollable factors are more likely to suffer with chronic helplessness (Maier & Seligman, 1976). These ideas were also extended to help researchers and clinicians think about the symptoms of depression. Seligman and colleagues proposed the model of learned helplessness was essential for working with people with depressive symptomatology (Seligman, 1992).

***Theoretical links with the current study findings***

The current study illustrates the difficulties participants encountered trying to fulfil their aspirations for education and employment. Participants described the many practical and physical consequences of CF encountered in education and employment, repeated absences and adherence to a demanding and complex treatment regime were reported as particularly problematic. In particular, a developmental trajectory of CF intruding as educational difficulty increased was discussed and participants spoke of a gap widening both

academically and socially between them and their peers. Many described the actions of others as particularly hindering their abilities to succeed, with several describing experience of bullying and dismissal and refusal of employment because of CF. The reality of struggles to achieve and maintain educational and occupational performance because of CF had a significant impact on their belief and expectations of achieving educational and occupational success. As a consequence, many participants withdrew from their aspirations and subsequent attempts at educational and occupational attainment.

Participants' continued exposure in education and employment to the difficulties described above can be understood in terms of adverse stimuli which they cannot escape (an uncontrollable event). They understood their continual attempts to succeed were constantly thwarted by periods of absence, adherence to a demanding treatment regime and on some occasions the actions of others, all of which appear outside of their control. It is possible therefore that over time participants have learnt that their response is independent of outcome. Essentially, they learn that nothing they can do will effect change and therefore give up trying: the development of learned helplessness. To date, there is no research within the CF literature which proposes poor educational and occupational achievement in people with CF is associated with the presence of learned helplessness. The way participants made sense of their experiences (attributed) is consistent with the theory of learned helplessness and therefore may be useful when explaining the phenomena they are describing, a novel contribution therefore of the current study to the existing evidence base.

Attribution theory can also be useful in making sense of the current study findings. All participants describe how CF has prevented the attainment of aspirations and educational and occupational success (external attribution). However, several also spoke of how their poor adherence to treatment and the limited effort they put into education in adolescence also influenced attainment (internal attribution). Interestingly, several participants spoke of how their withdrawal from aspirations about achieving education and career goals were deliberate attempts to establish different priorities, primarily maintenance of health. In terms of attribution theory, this may be understood as attempts by the individual to avoid failure with education and employment and preserve a positive self-image.

A key assumption of attribution theory is that the attributions or perceptions used to explain the success or failure by any given individual influence future effort and motivation. Specifically, those individuals who attribute success or failure to internal, unstable and controllable factors may be more likely to persevere in education and those who attribute success or failure to external, stable and uncontrollable factors may be more likely to

disengage (Weiner, 1980). The findings from the current study support this. As mentioned, the majority of participants in the current study attributed their failure with education and employment to the practical difficulties associated with CF (external factors). It was apparent their difficulties with CF were not isolated to a particular situation or time, their experience of difficulty was often described across multiple situations and times (stable). Participants also spoke of their inability to change the situation; they spoke of how because of CF they are always going to have periods of absence and require adherence to a demanding treatment regime (uncontrollable).

Interestingly, whilst the practical consequences of CF can be seen as external, the physical consequences of CF i.e. illness, can be understood as internal, as this resides within the individual. Maier and Seligman (1976) found that those individuals who attribute failure to internal, stable and uncontrollable factors are more likely to suffer with chronic helplessness; this is consistent with the findings from the current study and may be worth exploring in future research.

In summary, findings from the current study have been shown to have important links with the theory of attribution and learned helplessness. Both these psychological theories provide novel insights in understanding the educational and employment experiences of people with CF and it is hoped will contribute to the developing evidence base in CF.

## **Methodological Considerations**

The next section will discuss methodological considerations of the current study by outlining methodological limitations followed by discussion of the methodological strengths.

### **Methodological Limitations**

#### ***Selection and responder bias***

For the recruitment of study one and two, clinicians attached to the Leeds regional Adult CF centre identified and approached participants to ask about their interest in the study. Whilst there were a number of strict inclusion criteria clinicians needed to adhere to in study two, there is a possibility that clinicians approached those patients that were known to them, were more amenable to the process of research and more likely to agree to take part. There is also a possibility (especially in study two) that those who agreed to take part had very different experiences to those who declined participation. In the recruitment of both studies therefore, there is a possibility of selection bias.

Due to the nature of this type of research there is also a possibility in both study one and two that participants may have been influenced by responder bias. There are a number of factors which may have influenced this: there is a possibility that participants may have felt uncomfortable sharing their experiences for fear of judgement. There is also the possibility (in study one especially) that there were concerns that the data collected may influence the receipt of benefits.

#### ***Sample***

Both study one and two recruited participants from the Adult CF Centre at St James's Hospital in Leeds. It is possible therefore that participants recruited from different CF centres around the UK or the world may have provided different experiences of education and employment.

In study two, only six participants were recruited, it could be argued therefore that 'saturation' of the data was not reached. Thus, there may be other theoretical insights present in young people's experiences of education and employment which are absent in the data (Charmaz, 2006). However, the author defends this position by arguing the sample chosen represents a broad range of experiences, encompassing those who have and haven't

had experience of employment and those who want and don't want to pursue education and employment in the future. The sample also included an equal number of females and males.

Another possible limitation of the sample was that two participants were on the referral list for transplant. It may be possible therefore, that their experiences were confounded by disease severity.

### ***Researcher bias***

In the current study a constructionist version of GT was adopted and by doing so it was acknowledged my perspective and position (both as a person and theorist) may have shaped and influenced the research process.

One possible form of bias is my experience as a psychologist in clinical training. As a psychologist in clinical training I am skilled in the active listening and talking with people around subjects which may be of some unease and difficulty for an individual. It is possible therefore that having these skills may have enabled participants to feel more at ease and able to express their experiences. In addition, much of my working career has centred on working with young people with physical health problems and some of the difficulties they can face. Although I did not have any prior experience of working with people with CF, my knowledge and understanding of the impact of physical health problems and particularly my interest in this field may have added an extra level of understanding and empathy which influenced data collection and analysis in the current study. Being a health professional however and in the context of this study a researcher, an inherent power imbalance exists. It is possible participants may have felt uneasy talking about their difficulties with education and employment with somebody they may have felt had not experienced the same. It is also possible that having had my own experiences and assumptions of education and employment may have been influential. Both these dynamics active in the current study may have influenced collection, analysis and interpretation of the data.

Another possible form of bias is my sex and age. Some of the participants may have found that being a female and reasonably close in age to them may have proved easier to relate to and share their experiences, for others however, this may have proved more difficult, again influencing data collection and analysis. It is also possible that being a stranger (having never met any of the participants prior to the study) enabled participants to openly share their experiences, though, there is also a possibility this hindered exploration and discussion of experience.

Although CF is more prevalent in Caucasians, it affects individuals of most racial and ethnic backgrounds (Grieve et al., 2011). Both myself and all the participants in the current study were Caucasian and from a western culture. It is possible therefore that the accounts provided and the interpretations made in the current study have an inherent, individualistic view of the world (Mkhize, 2004). It may be that if the participants and myself had been from a different racial, ethnic and cultural background, collection, analysis and interpretation of the data may have provided a different understanding of experience.

One further potential bias was my exploration of the CF and other chronic illness and disability literature. This directed and guided my thinking throughout the research process. It is possible that inferences drawn from this influenced data collection and analysis. Also, I had analysed data from study one prior to the start of study two which had enabled me to meet with many of the CF community, patients and health professionals, and provided some early insight into the educational and employment experiences of people with CF. It is possible therefore that early assumptions drawn from discussions and analysis of study one may have influenced the data collection and analysis of study two. In addition, all participants in study two took part in study one; again, potentially influencing the data collection and analysis of study two.

Finally, as described, the constructionist position recognises the researcher as an active agent in the research process and therefore acknowledges the inherent subjectivity in the construction of knowledge. It is possible therefore that had a different epistemological position been adopted, such as a positivist approach, the understanding of the data produced and the implications for the evaluation of the research may have differed (Marshall, 1986; Willig, 2008).

### **Methodological Strengths**

#### ***Large up to date UK survey***

Study one provides a large, up to date, UK survey of the educational qualifications and employment history of people with CF attending the Leeds regional Adult CF centre at St James's Hospital. Over two thirds of the patient population were reached and the response rate was high (97%) therefore it is likely the sample is representative of the patient population. In addition, clinicians were present to help those who had difficulty completing the survey; therefore it can be argued that the sample is not biased in favour of those with higher educational attainment and socioeconomic status.

### ***Relationship between attainment and socioeconomic status***

There are few studies in the literature which have examined the relationship between educational and occupational attainment and socioeconomic status in people with CF. The current study highlights the importance of this on the attainment of people with CF, and is therefore a unique contribution to the existing evidence base.

### ***GT methodology***

Much of the research carried out to date on workplace participation in people with CF has focused on samples of people in employment rather than those who are not and predominantly adopts an ‘illness focussed’ epistemological stance (Edwards & Boxall, 2010). There are few studies in the literature to date which have explored the views, experiences and understandings of educational and workplace participation in people with CF using qualitative methodology, and none that have examined the experiences of education and employment together. Study two provides insight into all these areas and offers explanations and understandings of the numerous factors, not just disease severity, which influence educational and workplace participation in people with CF. The findings from the current study provide real-world insight into both the lived educational and employment experiences of people with CF not in education and employment. Using grounded theory a theoretical model grounded in participants’ experiences has been developed providing some speculations as to why many do not fulfil their potential, a contribution not only to the existing evidence base on CF but perhaps that of other chronic illnesses and disability.

### ***Reducing bias***

#### Early vs. late diagnosis

In study one, the sample distinguished between early and late diagnosis of CF, which is rarely reported in other surveys. The majority of participants in study one had an early diagnosis of CF; therefore a potential survivor effect is unlikely to have biased findings.

#### Researcher reflexivity

Throughout the research process I reflected on my role as researcher and how my age, gender, ethnicity, personal experience of the subject and personal reactions to the research context and data might have influenced data collection and analysis in both study

one and two. A written account of possible bias was made explicit in Chapter III so that the reader can interpret and understand the research and consider any claims in relation to these.

#### Credibility checks

The author received regular supervision whereby she discussed the development and organisation of the data with her academic supervisor throughout the data collection and analysis of study two. She also took part in two separate peer supervision groups for qualitative researchers. This ensured the credibility of the analysis was checked and the interpretation of the data was not solely from the author's perspective. However, there may have been some value in employing further credibility checks in the current study. It may have been useful to have asked a second trained rater to rate a proportion of the transcripts to check for inter-rater reliability agreement. It may also have been valuable to have met with a participant and checked whether the theory which emerged fitted with participants' understanding of experience (participant validation) (Elliott, Fischer & Rennie, 1999).

#### **Summary**

There are a number of methodological limitations of the current study of which the reader should be mindful when interpreting the current findings. The author recognises the limitations of a single centre design, a small sample size in study two and the potential bias proposed by the selection and responses of participants and the subjectivity of the researcher. The author however, reflected on her role as researcher and made efforts to overcome potential bias throughout the research process, providing novel, theoretical insights grounded in participants' experiences into both the educational and employment experiences of people with CF. This not only contributes to the existing evidence base on CF but perhaps that of other chronic illnesses and disability.

## **Clinical Implications for Healthcare, Education and Employment Providers**

The current study provides insight into the numerous practical and prejudicial barriers which are preventing people with CF from achieving educational and occupational success, highlighting a number of important implications for healthcare, educational and employment providers. To try and improve the opportunities for people with CF these issues must be addressed.

### ***Increase CF understanding and awareness***

Findings from the current study and that of the existing evidence base suggest a need for education providers, employers and the wider society to be more aware and understanding of CF and the potential difficulties this presents in education and employment. There is therefore a need for CF clinicians to liaise with teachers, staff and employers working with young people with CF to help provide this. It is important for people with CF to feel that their CF and the difficulties associated with this are understood, especially in education, as relationships with teachers and pupils are essential for enhancing feelings of self-efficacy (Grieve et al., 2011); as is reported in the current study, feelings of self-efficacy can be influential in overcoming the numerous challenges and barriers faced by people with CF in education and employment.

### ***Provision of support and help in education***

With educational attainment being the factor most predictive of employment in people with CF, to improve the employment opportunities of people with CF there is a pressing need to intervene in education. Due to the demanding and progressive nature of CF, absenteeism from education will continue to prove a challenge for those with CF. In education, there is a need for educational providers to have more supportive and appropriate provisions put in place to help young people keep up with their studies when absent from education. Young people need regular systems in place to ensure they can access the work they need and if need be, be provided with one to one tuition or support. This also has implications for educational providers in hospital. Young people admitted to hospital need to be provided with an environment conducive to working so that they can ensure that when they are an inpatient they can keep up with their studies.

***Early intervention in education and socioeconomic status***

The developmental aspect of CF on education raises a key issue. It seems that the influence of CF on education becomes more of a challenge with age and increasing educational difficulty. The more difficulty and failure an individual faces because of their CF, the more likely their belief in their abilities to succeed are likely to dwindle. Early intervention in education therefore seems crucial. There is a need for understanding and awareness of CF and help and support to be put in place early on in education, so that this alleviates the accumulative effect of difficulty.

Findings from the current study found those from lower socioeconomic backgrounds were more likely to leave school at a younger age and less likely to achieve educational qualifications at degree level; there is a need therefore for clinicians and educational providers to put more support and resources in place to help this population of people.

***Improve access to and continuation in employment***

Access to seeking and sustaining employment in people with CF also needs to be improved. By improving understanding and awareness of CF it is hoped the perception that people with CF are not as capable in meeting the demands of a job as those in the general population is challenged, leading to a reduction in the prejudice and discrimination of people with CF, enabling both access and maintenance of employment to increase.

***Annual clinical reviews***

A way in which to monitor the developmental changes in educational needs and difficulty would be to incorporate a review of educational needs at each annual clinical review. This may lead to the development of an educational care plan which could be a useful tool in aiding transition to different educational providers such as college and university. It may also be valuable to include at these reviews allocated time to discuss any job-related issues or careers advice for young people with CF.

***Treatment adherence and disease mastery***

There is increasing need for both educational providers and employers to accommodate the demanding treatment needs of people with CF. Facilities and resources need to be put in place to ensure people with CF can adhere to treatment when in education and employment.

Well known in the literature, several participants in the current study reported difficulties in adolescence taking on the responsibility for the management of their treatment. Non adherence to treatment resulted in deterioration in health which resulted in more time absent from education. There is therefore a need for practical as well as emotional support from clinicians around this time for young people with CF. As reported in the current study, those who have increased confidence in their abilities to control their CF are more likely to succeed in education and employment.

### ***Preventing and reducing learned helplessness***

Understanding the current findings in terms of learned helplessness has important clinical implications for people with CF. If poor educational and occupational success in young people with CF is the consequence of learned helplessness it will be important for educational providers and employers to try and reduce the likelihood of individuals experiencing repeated aversive outcomes e.g. reduce the difficulties faced in education and employment by provision of support and help. It will be important to help individuals generate constructive attributions that enable them to continue to feel they can affect their situations through their own actions. By putting this support in place it is likely individuals will experience more desired outcomes e.g. the attainment of educational and occupational success, therefore reducing the likelihood of developing learned helplessness. Evidence suggests that experience with success can be successful in overcoming and preventing helplessness deficits (Maier & Seligman, 1976).

Holding these theories in mind also has important clinical implications for clinicians. Whilst non adherence to treatment in adolescence may be interpreted as adolescent rebellion, it may also be understood in terms of learned helplessness. For some individuals, non adherence in adolescence may be the consequence of individuals feeling helpless to affect change over their illness. It may be that recurrent episodes of being unwell and in and out of hospital leads to the belief that no amount of medication is going to make them better, and it is this which leads them to stop adhering: the development of learned helplessness.

Understanding poor educational and occupational attainment and non adherence in people with CF as the consequence of learned helplessness is novel. Young people may benefit from preventive interventions that inoculate them against learned helplessness and the means to improve their sense of efficacy in a constructive way if they are faced with situations in which they are helpless. It will be useful for team members to

normalise the difficulties experienced by young people and to help them think about ways they can manage situations constructively, subsequently challenging feelings of helplessness. It is important for clinicians to hold these theories in mind when working with young people with CF as this will enable a new way of thinking about the difficulties young people face and subsequently the interventions that can be put in place to try and help. It might also be useful for individuals to discuss these issues with a Clinical Psychologist where aspects of cognitive therapy can be explored.

### ***Challenging misconceptions***

Several participants in the current study demonstrate how beliefs about CF and their own abilities to succeed impacted on their experiences of education and employment. Whilst beliefs surrounding reduced life expectancy and risk of illness may be valid, beliefs surrounding the extent of this and their own capabilities need to be challenged. There is therefore a need to talk with patients from a young age and explore their beliefs about CF, the self and the future, to ensure any misconceptions can be challenged and in some cases, extinguished. People with CF need to be encouraged to have realistic, yet positive expectations for their future. It is evident from the current study that without self-belief and encouragement, educational and occupational success is all too likely not to be attained.

### **Summary**

To ensure the educational and employment needs of young people with CF are met, a collaborative and coordinated working partnership between educational, healthcare providers and employers needs to be established. We need to increase awareness and understanding of CF in the education system and workplace and the potential impact of this on school, college, university and working life and ensure these providers are informed and equipped to support the needs of people with CF. Young people need to be supported in the management of their care and together with these providers work towards reducing the burden of CF on their life.

### **Implications for Future Research**

Whilst the current survey provided some insight into the factors influencing educational and workplace participation in people with CF. It would be interesting to explore the influence of psychological distress (depression and anxiety), frequency of hospital admissions, daily time spent on treatment and quality of life on educational and occupational attainment.

Another possible area of future research would be to evaluate the effects of participation in the current study on participants' subsequent aspirations and educational and occupational outcome.

The sample chosen in study two was reasonably small and restricted in age range. It would be interesting therefore to conduct the same study in different age groups of people with CF and examine how the aspirations, beliefs and experiences of education and employment may differ.

A clinical implication of the current study was the possibility of incorporating into the annual clinical review for young people with CF discussion of educational need and career related issues and advice. It would be interesting therefore, to conduct a longitudinal study to explore the effects of this intervention on future educational and occupational outcome.

Finally, it may be interesting to examine the prevalence of learned helplessness in young people with CF facing difficulties with education and employment to examine how prevalent this issue may or may not be. Secondly, for those individuals found to be helpless it may be useful to pilot a form of therapeutic intervention such as cognitive therapy and examine whether this has any effect on reducing the deficits of learned helplessness. Furthermore, it may be useful to conduct a longitudinal study to examine the effects of this intervention on future educational and occupational attainment.

## CONCLUSION

1. In study one, a survey showed that people with CF are still below the national average for obtaining qualifications and paid employment. The relative contributions of hypothesised factors such as absence from school or the workplace due to ill health and lowered expectations in childhood were explored in study two, a qualitative exploration of the educational and employment experiences and understanding of the factors that influenced the development and attainment of aspirations of six young people with CF.
2. The qualitative study revealed that the participants had a variety of aspirations in childhood. Although the development of these had their origin in a number of personal and familial influences, the role of CF in the development and attainment of aspirations was clear. With increasing age, the influence of CF changed from a relatively benign influence (exposure to hospital environments) to a malign one. This involved repeated absences due to ill health and appointments, and intrusions because of the adherence regime. For some, it also involved an awareness of the reduced life expectancy in CF, though this was not always understood accurately.
3. For most, their experience of education was very negative, with practical and physical consequences of CF increasing the academic and social gap from their peers. All were able to discuss the positive and negative influences of individuals and institutions which hugely affected the impact of the CF. This pattern was repeated in the experiences of participants in the workplace.
4. These experiences shaped the way the participants saw themselves and their relationship with CF. For some, it had given them a desire to prove that they could overcome CF, and one had returned to education. Others had withdrawn from conventional education and employment, sometimes citing lack of progress with unhelpful systems at school or their workplace, others feeling that their priorities had changed and maintaining their health was both more important than and incompatible with returning to education or work.
5. The theoretical formulation that emerged reveals how the physical and practical consequence of CF and in some cases the actions of others presented many practical and prejudicial barriers preventing many from attaining the educational and occupational hopes they aspired to. The reality of these struggles to achieve and maintain educational and occupational performance because of CF, and worries

about their health and life expectancy had a significant impact on self-belief and belief in educational and workplace providers. Limited aspirations and self-belief lowered expectations of achieving educational and occupational success, resulting in a withdrawal from aspirations and subsequent educational and occupational attainment.

### **CLOSING SUMMARY**

The current study provides insight into the experiences of education and employment in young people with CF and explanation of the factors that influenced the development and attainment of aspirations, providing some speculations as to why many do not fulfil their educational and occupational potential. Whilst some research exists on the educational and occupational experiences of people with CF, the role of CF in the development and attainment of aspirations was a unique focus of the present study, and it is hoped that it may contribute towards a growth in the evidence base on CF and perhaps that of other chronic illnesses and disability.

Young people with CF need to be supported in overcoming many of the barriers faced in education and employment and encouraged to believe in a future which involves the attainment of educational qualifications and workplace participation. With educational and occupational success reliant on the presence of aspirations, it is important that barriers to achievement are extinguished and self-belief is fostered to ensure the educational and occupational outcomes of young people with CF improve.

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**APPENDIX A: EDUCATION AND EMPLOYMENT QUESTIONNAIRE**



*Education and Employment Questionnaire*

ID
----

Age: \_\_\_\_\_ Sex: Male  Female

Where are you living at the moment?

Living with partner  Living with parents  Living with friends/flatmates  Living alone  Other   
Please state: \_\_\_\_\_

Are you currently in a relationship?

Yes  No

When did you leave School?

15 years old  16 years old  17 years old  18 years old  Other (Please state age.)

What educational qualifications have you obtained?

Qualification	Approx how many?	What was the subject(s)?
GCSEs		
BTEC		
AS Levels		
A Levels		
NVQ		
HND		
Certificate of higher education		
Degree		
Masters		
Doctorate		
Other		



**Education and Employment Questionnaire**

ID
----

Are you working at the moment?

Yes  Job Title: \_\_\_\_\_

Full-time  Part-time  Voluntary

How many hours? \_\_\_\_\_

No  In education or training  Home-maker  Job seeker

Other  Please state: \_\_\_\_\_

**Brief Employment History (starting with your most recent or current job)**

Job Title/Description	From:	To:	Full time?

**What was or currently is your father's main occupation?**

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**What was or currently is your mother's main occupation?**

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## APPENDIX B: STUDY ONE PATIENT INFORMATION SHEET

The Leeds Teaching Hospitals   
NHS Trust



**Participant Information Sheet**  
**Version 2: 10<sup>th</sup> June 2011**

**Research study: Education and employment in adult cystic fibrosis patients: a questionnaire survey**

**Introduction**

We would like to invite you to take part in a research study. Before you decide, it is important to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. If there is anything that is not clear or if you would like more information please let us know.

**What is the purpose of the study?**

This study aims to survey the experiences of adult patients with cystic fibrosis (CF) in terms of their educational attainments and employment history. This will provide an up to date overview of important demographic information and illustrate the impact of the condition on education and opportunities for employment in the current adult CF population in Leeds. The study will be carried out by both the principle investigator (Miss Mary Claxton) who is currently carrying out a research project for a Doctorate of Clinical Psychology (DClin) and a Doctor attached to the Leeds Cystic Fibrosis Unit (Dr. Kate Williams), who is currently carrying out a research project for a Doctor of Medicine degree (MD). The study is being undertaken for educational purposes and will be used to produce background data relevant to both these studies, registered as separate pieces of research at the University of Leeds.

**Why have I been invited?**

We are asking you to take part in the study because you attend the Leeds Adult CF Unit for treatment.

**Do I have to take part?**

No, it is up to you to decide. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

**What will happen to me if I take part?**

You will be asked to complete one questionnaire which will ask questions about your employment history and educational achievements. This should take no more than 10 minutes.

**What happens to the information collected?**

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the Leeds CF Unit will have your name and address removed so that you cannot be recognised. None of your personal information will be included in the final report.

**What will I have to do?**

Read the information sheet and complete the consent form and questionnaire whilst attending outpatient clinic and waiting for medical review.

**What are the possible benefits of taking part?**

We hope that your taking part in the study and sharing your experiences will help us to learn about the impact of CF on education and opportunities for employment in the current Leeds adult population. The information received will also be used to identify areas of need and help us to improve our service for patients. If the results show an area where the CF team's pastoral care could be improved then this can also be addressed.

**What if there is a problem/ complaint?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact information at the end of the information sheet). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Leeds Cystic Fibrosis Unit. Alternatively you can contact Clare Skinner, Faculty Head of Research Support, Faculty of Medicine and Health Research Office, Rm 10.110, Level 10, Worsley Building, University of Leeds, Clarendon Road, Leeds, LS2 9NL.

If at any time during or after the survey you feel distressed for any reason you will be offered the chance to talk to a psychologist or social worker attached to the Leeds CF team.

**Contact Details:** Dr. Gary Latchford, Consultant Clinical Psychologist and Dr. Rob Whittaker, Clinical Psychologist: Telephone number: (0113) 206 5897. You can contact them directly or you can ask the researcher to arrange for someone to contact you.

**What will happen to the results of the research study?**

The results will be published in medical journals and disseminated at research seminars and conferences. You will not be identified in any way in the published reports. If you would like us to send you a copy of any papers published, please let us know.

**Who is organising and funding the research?**

The principle investigator for this study is Miss Mary Claxton and the study is being run between the Leeds Institute of Health Sciences at the University of Leeds and the Leeds Teaching Hospitals NHS Trust. The study is funded by a grant from the University of Leeds.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Derbyshire Local Research Ethics Proportionate Review Sub-Committee.

**Where can I find out more information?**

If you would like more information about this project, please contact:

Miss Mary Claxton  
Psychologist in Clinical Training  
DClin Program, Leeds Institute of Health Sciences  
University of Leeds  
Room G.04, Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ

Tel: 0113 3432732  
Email: [umamc@leeds.ac.uk](mailto:umamc@leeds.ac.uk)

**Thank you for thinking about taking part in this study.**

## APPENDIX C: STUDY ONE LETTER OF ETHICAL APPROVAL

11/EM/0222 Ethics opinion letter reissued 30 June 2011

### NRES Committee East Midlands - Derby 2

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839440  
Facsimile: 0115 9123300

30 June 2011

Miss Anna Mary Claxton  
Psychologist in Clinical Training  
The Leeds Teaching Hospitals NHS Trust  
Leeds Institute of Health Sciences, University of Leeds  
Rm G.04 Charles Thackray Building, 101 Clarendon Road,  
Leeds, LS2 9LJ

Dear Miss Claxton,

**Study title:** Education and employment in adult cystic fibrosis patients: a questionnaire survey  
**REC reference:** 11/EM/0222

The Proportionate Review Sub-Committee of the Derby 2 Research Ethics Committee reviewed the above application on 21 June 2011.

#### Provisional opinion

The Sub-Committee would be content to give a favourable ethical opinion of the research, subject to the following changes being made to the documentation for study participants:

- The Committee understands from your response at A6-2 on the IRAS form that in some circumstances you may need to break confidentiality. It was felt that the Participant Information Sheet should be updated to make clear this position.
- A consent form is not required for questionnaires, as consent is implied by completing the questionnaire. For the return of results to the participants, the Committee felt a reply slip would be more appropriate.
- The following sentence on Page 2 of the Participant Information Sheet indicates an objective of the study which has not been fully developed: 'If the results show an area where the CF team's pastoral care could be improved then this can also be addressed'. The Committee felt it would be better if this sentence were removed.

When submitting your response, please send the revised documentation underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

Authority to consider your response and to confirm the final opinion on behalf of the Committee has been delegated to Mr Phil Hopkinson.

Please let me know if you need any further clarification or would find it helpful to discuss the changes required with the lead reviewer.

11/EM/0222 Ethics opinion letter reissued 30 June 2011

The Committee will confirm the final ethical opinion within 7 days of receiving a full response.

#### Documents reviewed

The documents reviewed were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		10 June 2011
Evidence of insurance or indemnity		10 September 2010
Investigator CV		
Letter from Sponsor		10 June 2011
Other: CV Dr Kate Williams		
Other: CV Dr Gary Latchford		
Other: CV Dr Daniel Peckham		
Other: Information letter about the Trainee Clinical Psychology Research		10 June 2011
Other: Research Panel Constitution Letter		10 June 2011
Other: Research Panel Feedback		10 June 2011
Other: Sunderland REC Unfavourable Opinion letter		10 June 2011
Participant Consent Form	2	10 June 2011
Participant Information Sheet	2	10 June 2011
Protocol	2	10 June 2011
Questionnaire	1	10 June 2011
REC application		10 June 2011

#### Membership of the Committee

The members of the Ethics Committee who took part in the review are listed on the attached sheet.

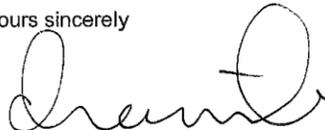
#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EM/0222

Please quote this number on all correspondence

Yours sincerely

pp 

**Mr Phil Hopkinson**  
Chair

E-mail: carol.marten@nottspct.nhs.uk

Enclosures:

*List of names and professions of members who took part in the review*

## APPENDIX D: STUDY TWO LETTER OF ETHICAL APPROVAL


**National Research Ethics Service**

NRES Committee East Midlands - Derby 2  
 The Old Chapel  
 Royal Standard Place  
 Nottingham  
 NG1 6FS

Telephone: 0115 8839440  
 Facsimile: 0115 9123300

22 June 2011

Miss Anna Mary Claxton  
 Psychologist in Clinical Training  
 The Leeds Teaching Hospitals NHS Trust  
 Leeds Institute of Health Sciences, University of Leeds  
 Rm G.04 Charles Thackrah Building, 101 Clarendon Road,  
 Leeds, LS2 9LJ

Dear Miss Claxton,

**Study title:** Education and employment in adult cystic fibrosis patients: a questionnaire survey  
**REC reference:** 11/EM/0222

Thank you for your letter of 30 June 2011, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority  
 The National Research Ethics Service (NRES) represents the NRES Directorate within the  
 National Patient Safety Agency and Research Ethics Committees in England

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC – optional. Indicate where final versions of documents should be provided to the committee for information, e.g. information sheet

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering Letter		10 June 2011
Evidence of insurance or indemnity		10 September 2010
Investigator CV		
Letter from Sponsor		10 June 2011
Other: CV Dr Kate Williams		
Other: CV Dr Gary Latchford		
Other: CV Dr Daniel Peckham		
Other: Information letter about the Trainee Clinical Psychology Research		10 June 2011
Other: Research Panel Constitution Letter		10 June 2011
Other: Research Panel Feedback		10 June 2011
Other: Sunderland REC Unfavourable Opinion letter		10 June 2011
Participant Consent Form	2	10 June 2011
Participant Information Sheet	3	30 June 2011
Protocol	2	10 June 2011
Questionnaire	1	10 June 2011
REC application		10 June 2011
Response to provisional opinion		30 June 2011

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

11/EM/0222

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely




**Mr Phil Hopkinson**  
Chair

E-mail: [carol.marten@nottspct.nhs.uk](mailto:carol.marten@nottspct.nhs.uk)

Copy to:

*Ms Anne Gowing, Leeds Teaching Hospitals NHS Trust, R&D  
Department, 34 Hyde Terrace, Leeds, LS2 9LN*

*Ms Rachel de Souza, Faculty Research Office, Rm 10.110, Level 10,  
Worsley Building, Clarendon Way, Leeds, LS2 9NL*

## APPENDIX E: STUDY TWO PATIENT INFORMATION SHEET



UNIVERSITY OF LEEDS

## Participant Information Sheet

Version 1: 19<sup>th</sup> April 2011

### Research Study: Education and Employment: The beliefs, aspirations and experiences of young people with Cystic Fibrosis: A qualitative study.

#### Introduction:

We would like to invite you to take part in a research study. Before you decide, it is important to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. If there is anything that is not clear or if you would like more information please let us know.

#### What is the purpose of the study?

I am a psychologist in clinical training, undertaking doctoral research as part of my clinical qualification. I am based in the Leeds Institute of Health Sciences at the University of Leeds and employed by the Leeds Teaching Hospitals NHS Trust. I am conducting a study to find out the educational and employment experiences of young people with Cystic Fibrosis. In particular the beliefs young people hold about the consequences of Cystic Fibrosis and how these influence the development and formation of aspirations and educational and occupational outcome. This study is being undertaken for educational purposes as part of my doctorate degree. The results of the study will help us to better understand why patients with CF might not achieve their educational and occupational potential and what can be done to better facilitate, support and develop participation in education and work life.

#### Why have I been invited?

We are asking you to take part in the study because we are interested in hearing about the experiences young people with CF have had of education and employment and the possible impact of CF on this. You have been asked to take part following recommendation from a member of the Leeds CF Medical Team.

#### Do I have to take part?

No, it is up to you to decide. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

#### What will happen to me if I take part?

You will be asked to take part in an interview that will be conducted by myself. The main purpose of the interview is to ask about any experience of education and employment. In particular, the beliefs you hold about the consequences of Cystic Fibrosis and how these may have influenced the development and formation of aspirations and educational and occupational outcome. The interview will take place at a location convenient for you; either at the Leeds Cystic Fibrosis Unit at St James's Hospital or alternatively your home, and will

last approximately 30-60 minutes. You will only have to take part in the interview once. However, if during the interview you feel that you would like to stop and continue with the interview at another time then that can be arranged. The interview will be conducted at a time convenient for you. All interviews will be audio-taped so that they are recorded accurately and typed up at a later date. All travel expenses incurred as a result of taking part in this study will be reimbursed.

**What happens to the information collected in the interview?**

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised. None of your personal information will be included in the final report. All tapes will be kept in locked filing cabinets and destroyed after the study is completed. The only exception for breaching confidentiality is if you give the researcher information that suggests you might be at serious risk. In that case the researcher will inform you that she has to break the confidentiality and report this concern to the relevant authorities.

**What will I have to do?**

Nothing, if you would like to take part and agree to be contacted, I will make the first contact in order to answer any questions you may have and arrange the interview.

**What are the possible benefits of taking part?**

We hope that your taking part in the study and sharing your experiences will help us to learn more about education and employment issues in Cystic Fibrosis.

**What if there is a problem/complaint?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact information at the end of the information sheet). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Leeds Cystic Fibrosis Unit. Alternatively you can contact Clare Skinner, Faculty Head of Research Support, Faculty of Medicine and Health Research Office, Rm 10.110, Level 10, Worsley Building, University of Leeds, Clarendon Road, Leeds, LS2 9NL.

If at any time during or after the interview you feel distressed for any reason you will be offered the chance to talk to a psychologist attached to the Leeds CF team.

**Contact Details:** Dr. Gary Latchford, Consultant Clinical Psychologist and Dr. Rob Whittaker, Clinical Psychologist: Telephone number: (0113) 206 5897. You can contact them directly or you can ask the researcher to arrange for someone to contact you.

**What will happen to the results of the research study?**

The results will be published in medical journals and disseminated at research seminars and conferences. You will not be identified in any way in the published reports; anonymised quotes will be used to illustrate the themes that emerge. If you would like us to send you a copy of any papers published, please let us know.

**Who is organising and funding the research?**

The principle investigator for this study is Miss Mary Claxton and the study is being run between the Leeds Institute of Health Sciences at the University of Leeds and the Leeds Teaching Hospitals NHS Trust. The study is funded by a grant from the University of Leeds.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the North East Sunderland Research Ethics Committee.

**Where can I find out more information?**

If you would like more information about this project, please contact:

Miss Mary Claxton  
Psychologist in Clinical Training  
DClin Program, Leeds Institute of Health Sciences  
University of Leeds  
Room G.04, Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ

Tel: 0113 3432732  
Email: [umamc@leeds.ac.uk](mailto:umamc@leeds.ac.uk)

**Thank you for thinking about taking part in this study.**

## APPENDIX F: STUDY TWO CONSENT FORM



UNIVERSITY OF LEEDS

**Consent Form**

Version 1: April 2011

Participant Identification Number for this study: \_\_\_\_\_

Research Study: **Education and Employment: The beliefs, aspirations and experiences of young people with Cystic Fibrosis: A qualitative study.**

Name of Researcher: Mary Claxton

Please initial box

1. I confirm that I have read and understand the information sheet dated \_\_\_\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of my data collected during the study, may be looked at by individuals from the research team at the University of Leeds or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to quotes being used in the writing of a report on the understanding that my anonymity is maintained?
5. I agree to the interview being audio-taped.
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant\_\_\_\_\_  
Date\_\_\_\_\_  
Signature\_\_\_\_\_  
Name of Researcher\_\_\_\_\_  
Date\_\_\_\_\_  
Signature

## APPENDIX G: INTERVIEW SCHEDULE

### INTERVIEW SCHEDULE

Version 5: October 2011

#### Part 1: Introduction

TEXT GARY	<input type="checkbox"/>
Start recording	<input type="checkbox"/>
Introduce self	<input type="checkbox"/>
Thank you for meeting today	<input type="checkbox"/>
Go through PIS & answer questions	<input type="checkbox"/>
Happy to continue? Sign consent form.	<input type="checkbox"/>

**1. I would like to start talking with you today by asking you why you decided to take part in this research?**

Was there any particular reason?

Any hopes?

So you're an adult now and I am assuming you have been living with CF since you were a small child.

**2. Can you tell me a little about your experiences of living with Cystic Fibrosis?**

When did you first understand that you had Cystic Fibrosis?

How old were you? Can you remember who told you?

What was this like?

Can you remember any emotions you felt?

**3. At this stage, what was your understanding of the condition?**

Did you have any awareness/understanding of the impact of the condition?

**Reflections on Childhood:**

**I'd like to start talking with you today about when you were a child...**

**4. Thinking back to when you were a child what were your thoughts about the future?**

What did you want to be when you grew up?

What did you think you might do?

What were your hopes?

**5. Why do you think this was?**

What influenced your hopes at this time?

What factors do you think played a role in shaping and forming these hopes?

**6. Do you think Cystic Fibrosis influenced the development of these hopes?**

How? Why?

**7. Do you think Cystic Fibrosis affected your thoughts about the future?**

Did CF affect your thoughts about what you wanted to be when you grew up?  
How? Why?

Did CF affect what you thought you might do? How? Why?

**Reflections on School:**

**I would like to move forward now to when you were an adolescent and hear a bit about your time at school...**

**8. When you were 15 or 16, what were your thoughts about staying on in school or going to college?**

**9. Why do you think this was?**

What influenced your intentions?

What factors do you think played a role in shaping and forming these thoughts?

**10. Do you think Cystic Fibrosis affected your intentions to stay on in school or go to college?**

How? Why?

**11. What did you end up doing?**

Why?

Did you go onto college or university?

Why/ Why not?

**12. Do you think Cystic Fibrosis affected this decision?**

How? Why?

**13. Do you think having Cystic Fibrosis has affected your education?**

How? Why?

### Reflections on Employment:

We discussed at the beginning of the interview what you thought or hoped as a child you would be doing when you grew up, moving forward now to the present...

14. What did you *actually* end up doing?

15. Why do you think this was?

16. What factors do you think played a role in determining this?

17. Do you think Cystic Fibrosis affected this?

How? Why?

18. Do you think having Cystic Fibrosis has affected your career?

How? Why?

### Closing Questions...

19. Looking back, has living with Cystic Fibrosis affected your hopes and plans for the future?

How? Why?

20. Does Cystic Fibrosis affect the way you live your life now?

How? Why?

21. Knowing what you know now, if you had the opportunity to go back again would you do anything differently?

What?

How?

Why?

<b>22. Is there anything else that you think may be important or useful for me to know about?</b>	
Do you have any questions?	<input type="checkbox"/>
Is there any part of the interview that you would like to be excluded?	<input type="checkbox"/>
Thank you for meeting today	<input type="checkbox"/>
<b>TEXT GARY</b>	<input type="checkbox"/>

## APPENDIX H: EXAMPLE TRANSCRIPT

<p>Limited awareness of CF</p> <p>Understanding of hospital admission → knew 'I was poorly'</p> <p>Didn't want to stay in hospital / go to college</p> <p>Didn't like school</p> <p>Bad experience of high school</p> <p>Bullied</p> <p>Missed a lot of school</p> <p>Left school early</p> <p>Behind on work</p> <p>Teachers didn't understand</p> <p>Reasons for leaving school.</p> <p>Struggling for help</p> <p>Not understanding because behind</p> <p>Expectation of teacher to do work in hospital</p> <p>Difficulty doing work in hospital</p> <p>Struggling</p> <p>Lack of understanding</p> <p>Seemed right off with because of absence</p> <p>Subjects not understanding of CF</p>	<p>62 P Not really cos I didn't know it was what CF I had,</p> <p>63 yea I just thought I was in hospital cos I was poorly</p> <p>64 I OK. OK, I'd like to move forward now to being at</p> <p>65 school and when you were an adolescent OK, and hear a</p> <p>66 bit about your time at school. So when you were 15 or</p> <p>67 16, or about those stages, what were your thoughts about</p> <p>68 staying in school?</p> <p>69 P I didn't want to, I didn't like school, I didn't have</p> <p>70 a good experience at high school (I OK). I got bullied a</p> <p>71 lot and I missed a lot of school and and I left in year 10. (I</p> <p>72 OK) So I didn't stay full term at school anyway (I OK)</p> <p>73 cos I was bullied a lot and I was behind on work and</p> <p>74 teachers didn't seem to understand. SO</p> <p>75 I OK, so what didn't they seem to understand?</p> <p>76 P Like if I, I'd sit there with my hand up in class</p> <p>77 saying I don't understand the work cos I'd be so far</p> <p>78 behind and they'd say well you should do your work in</p> <p>79 hospital and I said but I do but you don't send the same</p> <p>80 work. So I used to struggle a lot and they didn't</p> <p>81 understand and a lot of them just, I don't know they just</p> <p>82 seemed right off with me because I wasn't there all the</p> <p>83 time. (I OK) they just weren't that understanding about</p> <p>84 my CF wasn't the school.</p>	<p>Limited CF awareness</p> <p>Didn't want to stay in school</p> <p>Didn't like school</p> <p>Bullied</p> <p>CF absence</p> <p>Left school early</p> <p>Reason for leaving school</p> <p>Fell behind on work</p> <p>Lack of understanding</p> <p>Teacher expectation</p> <p>Difficulty getting work</p> <p>Struggle</p> <p>Lack of understanding</p> <p>School response to absence</p> <p>Lack of understanding</p>
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